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Development and Evaluation of a Creative Expression Intervention Programme for People with Dementia in China

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Development and Evaluation of a Creative Expression Intervention Programme for People with Dementia in China

Hong Li

A thesis submitted for the degree of Professional Doctorate in
Health (DHealth)

University of Bath
Department of Health

October 2015

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Development and Evaluation of a Creative Expression Intervention Programme for People with Dementia in China.

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Contribution

The author had a full role in the conception and design of the study, as well as participating in part of the research activities, the analysis and interpretation of data, drafting and revising the thesis and the final submission.

Mrs. Chen Xiaohuan, Director of Nursing Department of Fujian Provincial Hospital, and Mrs. Chen Qiuhua, head nurses of geriatric ward, helped to recruit the participants.

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Abstract

Aim: The aim of this study was to develop and evaluate an evidence-based creative expression therapy for Chinese people with dementia in hospitals, LTC settings and household.

Background: Creative expression (CE) has been shown to be effective for engagement of both people with dementia and carers to communicate in the USA. However, there are limited cross-cultural studies of psychological therapy of people with dementia in China.

Method: The overall research strategy is a mixed method. To develop standard CE programme, action research was conducted by three sequential sessions in the geriatric wards, long term care institution and patients' homes respectively. 7 rounds of action research cycle including plan, action, observation, reflective discussion was complemented and 31 people with dementia received CE intervention and evaluating by means of observation, semi-structure interview. The following evaluation research is a controlled trial for people with dementia in LCT settings and hospitals. 91 cases of people with dementia were recruited and divided into two groups. While a series of social contact activities were conducted on the 48 cases control group, the revised CE intervention carried out on the 43 cases test group, both twice weekly for 6 weeks. The primary outcome was measured by MMSE、QOL-AD、CSDD and SFACS in week 0, week 7, week 10.

Findings

For the social communication and communication of basic needs in SFACS score, pleasure and general alertness mood by OERS, the test group

presented significantly better effect than the control group ($P < 0.05$). Although both group had a decline effect on CSDD score, the test group were maintaining lower 1month after intervention ($P < 0.05$). Thus the revised CE programme may improve the communication ability and alleviate depression of people with dementia significantly .However, although the quality of life is less affected, it showed a rising tendency after CE programme.

Conclusions:

This study added trans-cultural evidence on dementia treatment and developed a standard and effective creative expression intervention on Chinese people affected by dementia.

Key words: People with Dementia; Creative Expression; Action research
Non-pharmacological intervention

Abbreviations

Abbreviations	The full name
CE	Creative Expression
CSDD	Cornell scale for depression in dementia
FACS	The Functional Assessment of Communication Skills
LTC	Long Term Care
MMSE	Mini-Mental State Examination
MUNSH	Memorial University of New-foundland Seale of Happiness
OERS	Observed Emotion Rating Scale
QOL-AD	Quality of Life-Alzheimer's Disease
SC	Social Contact
SMCR	Berol's Model of Communication
TS	TimeSlips

Chapter 1: Introduction

Population ageing, which generates many challenges, is taking place in every country. World population is predicted to increase by 3.7 times from 1950 to 2050, but the number of those aged 60 and over will increase by a factor of nearly 10 (Bloom, 2011). The Chinese population above 60 years of age will be expected to increase from 12% in 2009 to 31% in 2050 (Zhu, 2012).

Prevalence of dementia increases almost exponentially with age (Iliffe, 2012). There are currently nearly 36 million people with dementia in the world. The numbers of people living with dementia worldwide is expected to double every 20 years. A survey conducted in Fuzhou, China showed a prevalence of 7.3% among elderly people over 65-year (Li, 2008). The ageing of the population means that the number of people with dementia would also grow in future decades with consequent implications for care provision, care burden and public expenditure (Cahill et al, 2012).

Dementia is a progressive condition that largely affects older people impacting with their memory, language, ability to communicate, mood and personality. Dementia is more common in older people with a decline or loss of mental abilities (the cognitive functions such as judgment, thinking, behaviour, and language). These losses not only impair a person's ability to function independently, but also have a negative impact on quality of life and relationships (Burns, 2009). Many people with dementia eventually become totally dependent on others. As a global health problem, dementia takes a heavy toll on people, society and the economy. (Bloom, 2011)

Dementia may be caused by irreversible as well as treatable causes. Most cases of dementia tend to progress unless the causes is treatable and reversible. Treatment may include medication and Non-pharmacologic therapy. To avoid the side-effect, there are various non-pharmacologic therapy methods in the world, which have shown benefits, as slowing the progression of cognitive competence, alleviating behavioural symptoms, preserving independence in daily activities, and improving the perceived life quality. The American Psychiatric Association concluded that non-pharmacological psychosocial treatments for dementia can be divided into four broad groups: behaviour-oriented, emotion-oriented, cognition-oriented, and stimulation-oriented. Besides, researchers raised a social model as the philosophy of non-pharmacological treatment. They advocated patient- centred care culture and tried to understand the emotions and behaviours of the people with dementia by placing them within the context of their social circumstances.

Creative storytelling, named TimeSlips by the developer from Center on Age & community of Milwaukee of University of Wisconsin, as one of non-pharmacologic treatments is a group storytelling programme for people with dementia that encourages open storytelling in people with dementia by stimulating imagination rather than relying on factual reminiscence (TimeSlips Creative Storytelling Project, 2011). Since 2006, researchers have used creative expression (CE) programmes to improve the quality of care and life of people with dementia in long-term care (LTC) settings (Bernfeld & Fritsch, 2006). It inspires others to see beyond loss to recognize their strengths; and improves the quality of life of people with dementia and their caregivers. In

addition the creative storytelling programme emphasised the uniqueness of persons and enabled them to feel included, supported, and valued. Creative expression programme has been shown to be effective for engagement of both people with dementia and carers to communicate in the USA.

However, there were limited cross-cultural studies of behavioural and psychological therapy of people with dementia in China. Although some non-pharmacological therapies used in Chinese people with dementia was reported, but rarely have they been standardised, adequately evaluated or systematically implemented. It is worth to explore what is the suitable creative storytelling programme for Chinese people with dementia and what impact it would produce to use the creative expression intervention in China. Therefore, the purpose of this study is to develop a suitable creative expression (CE) programme for Chinese people with dementia; to evaluate effectiveness of this treatment achieved in Chinese dementia people.

A qualitative action research was conducted to develop a standard CE programme protocol on people with dementia in Fuzhou, which would be a practical guide for hospitals, community, long-term care settings and homes. The study have carried out 3 sequential sessions in geriatric wards, long term care settings and their homes respectively and total 7 rounds following the process of plan-action-observe-rethinking cycle on total 31 cases of people with dementia. The research team participated in the implementation, modification and improvement of the programme on the basis of the data from observation, semi-structure interview and tools.

Prior to the quantitative evaluating study, three preliminary studies were undertaken: a survey on happiness of elders living in Fujian provincial LCTs, a small sample pilot study to evaluate the TimeSlips on people with dementia from geriatric wards, a Chinesization study to determine the reliability and validity of the Chinese Version of the Functional Assessment of Communication Skills (CV-FACS) . The following evaluation research design was a controlled trial for dementia with participants in rest-homes and hospitals, while a series of social contact activities were conducted on the control group ,the creative storytelling intervention carried out on the test group. The primary outcome measures were cognitive state examination, ability to communicate, quality of life, mood, etc. This study was anticipated to added trans-cultural evidence on dementia treatment and to develop a standard and effective behavioural intervention and nursing practice on Chinese dementia people.

Chapter 2: Literature Review

1 The epidemic situation of dementia

1.1 Population ageing

Population ageing that generates many challenges is taking place in every country. World population is predicted to increase 3.7 times from 1950 to 2050, but the number of those aged 60 and over will increase by a factor of nearly 10 (Bloom, 2011). China has entered an ageing society as well. The Chinese population above 60 years of age is growing at 3.3% annually and will be expected to increase from 12% in 2009 to 31% in 2050 (Zhu, 2012). Six distinguished features of ageing population in China are: 1) large size of population, a population of over 1.3 billion people, of whom 160 million are aged 60 and older; the largest ageing population in the world; 2) rapid speed of development, increasing at a rate of 5.96 million per year from 2001 to 2020 and then 6.2 million per year from 2021 to 2050, and is expected to exceed 400 million by 2050, accounting for 30% of its total population (Kinsella et al, 2009) experiencing population ageing and the challenge of caring for frail older adults; 3) the imbalance of regional development; 4) significant inversion between urban and rural; 5) more female population; 6) ageing faster than modernization.

1.2 Definition of dementia

Dementia is more common in older people. The World Health Organization (WHO) defines dementia as follows: "Dementia is a syndrome in which there is deterioration in memory, thinking, behaviour and the ability to perform

everyday activities.” (WHO, 2012) Dementia is an umbrella term for a biomedical concept that describes “symptoms that occur when the brain is affected by specific diseases and conditions” (Alzheimer Society, 2007). However, generally diagnoses of dementia are still not made until they are quite far into the course of the disease, even though helpful interventions could be started much earlier.

1.3 Diagnosis of dementia

Earlier recognition of dementia can assist people affected by dementia and their families by decreasing anxiety about changes in memory, thinking, mood or behaviour and making use of the resources that will be needed in the future (Iliffe et al., 2002). There are several different diagnostic criteria for dementia which have been shown to have good reliability (Knopman et al., 2001). However, the way in which a general diagnosis of dementia (rather than Alzheimer’s disease or vascular dementia) could be made following the typical process of assessment (figure2-1).

A diagnosis of dementia should be made after an assessment process, which should include: history, neuropsychological test, physical examination and other appropriate investigations (Jia, 2011).

Besides family history, occupation, educational level, etc, the medical history may comprise reported acquired cognitive deficits in more than one domain: memory lost , aphasia , apraxia, agnosia, or disorder of abstract thinking or judgment, as well as being interfered with social and/or activity function. The

data should be collected as detail as possible from self-reporting and knowledgeable informants. A suspected diagnosis could be made after examination of cognitive complement by simple tools such as The Mini Mental State Examination (MMSE) , Clock Drawing Test (CDT) , Activity of Daily Living Scale(ADL) , etc. To make sure the general diagnosis of dementia physicians also should eliminate disturbance of consciousness, delirium, temporary confusion and mental retarded caused by drugs or toxicant, etc.

It is recommended to apply the cognitive testing, for instance, Clinical Dementia Rating (CDR), Severe Impairment Battery (SIB) or Global Deterioration Scale (GDS) to determining dementia severity. To acquired further diagnosis of subtypes, physicians should combine further clinical data including history, neuropsychological state, physical and neural examination, investigation (humoral test, structural imaging, gene detection, etc.)

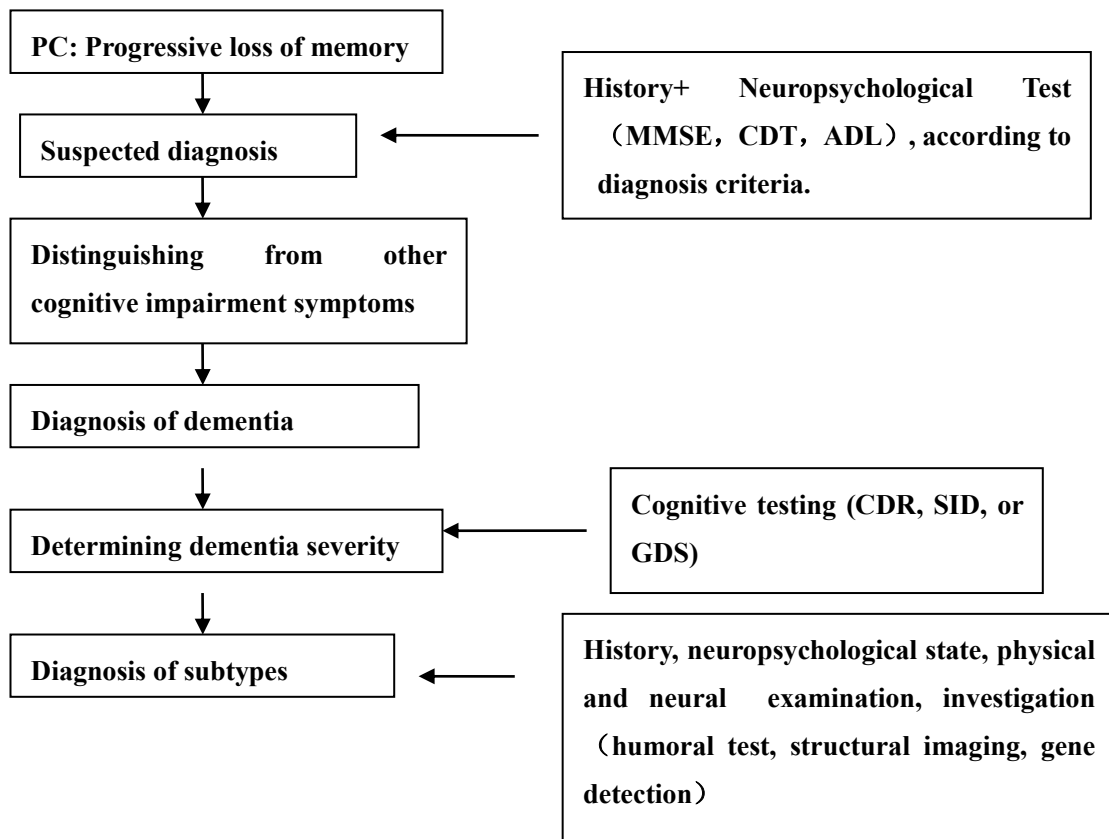


Figure 2-1 General process of assessment for dementia

The use of brief cognitive assessment is essential to make a clinical suspected diagnosis of dementia, which consist of testing attention and concentration, orientation, immediate and delayed memory, and higher cortical function including praxis, language etc. The most widely used is the 30-item Mini Mental State Examination (MMSE). Even the normative cut-off points to assist in the diagnosis of dementia, they should be interpreted cautiously, in view of many other factors involved and the possibility of high false-positive rates (White et al., 2002e). For an example, to understand the sensitivity of different cut-off criteria of MMSE, a survey conducted in 2911 cases of normal elders in Beijing by MMSE. The accordance rate was 46.8% by cut-off criterion I (Illiterate group ≤ 14 , literate group ≤ 19), while criterion II (Illiterate group ≤ 17 , primary group ≤ 20 , middle school and above ≤ 24) and criterion III (Illiterate

group ≤ 19 , primary group ≤ 22 , middle school and above ≤ 26) was 57.5% and 93.2 % respectively.(Li, 2001)

Advantages of those standardised scales include easy design, operating conveniently, taking short time and good reliability. Also the facts that norms are available, that severity of cognitive impairment can be quantified and easily communicated to others, that they serve as a useful baseline from which future change (for example, deterioration in the case of suspected dementia or improvement on medication or when delirium/depression resolves) can be accurately determined. However, the potential limitations related with interpretation, particularly of the MMSE, include demographic variables such as educational level and sensitivity to depression (Orrell et al., 1992), age and gender, other factors that are associated with skills, language, prior level of functioning, any sensory impairments, psychiatric illness or physical/neurological problems. For example, people with low education, language impairment or habits of native language tend to get false positive results, while well-educated people tend to get false negative results leading to overlook of mild cognitive impairment. Furthermore, the simple measurements have no time limit and no recognizing items for memory either. Also there is some learning effect variance in terms of repeated measurements reliability, particularly when standardised instructions and procedures are not followed. Thus these screening measures may not be sensitive when used as differential diagnosis of subtype and follow-up tools (Dai , 2013).

Besides, in terms of sub-sections' internal validity, MMSE screens domains of orientation to time and place, attention and memory, concentration, and

language and praxis but might not reflect some important cognitive functions adequately, such as less sensitive to frontal executive dysfunction, which is frequently more prominent than memory or other cognitive deficits in non-Alzheimer's disease dementia (NAD). Therefore, MMSE might probably miss the screening of dementia, NAD in particular (Kim, 2013).

1.4 Prevalence of dementia

The number of people with dementia is steadily rising with the population ageing. An estimated 36 million people with dementia is living in the world, whereas 28 million of those do not have a diagnosis. If this tendency continues, the numbers of people with dementia worldwide is expected to double every 20 years. By 2050 it is projected there will be 115 million people with dementia worldwide, 71% of whom will live in developing countries (Alzheimer's Society, 2014). With regard to dementia in the UK, in 2013, there were 815,827 people with dementia in the UK. 773,502 of these people with dementia were aged 65 years or over (Alzheimer's Society, 2014). There are currently nearly 5.3 million Americans have AD. In 2050, the incidence of AD is expected to approach nearly a million people per year, with a total estimated prevalence of 11–16 million people in the USA (Alzheimer's Association, 2010).

However, there is not large sample prevalence study of dementia in China yet. Nevertheless, a 4-city investigation showed a 5.7% prevalence rate (Zhang, 2006), while a 11-city investigation showed elderly dementia prevalence rate is 0.38 ~ 2.25% (Dong et al, 2013). By this token, there are about 6 million people with dementia in China, predicts that by 2025 will increase to 10.09

million people (Han et al,2011). A survey conducted in Fuzhou in China shows a prevalent of 7.3% among elderly people over 65-year (Li et al. 2009). Based on a search of Chinese and English databases including 76 dementia prevalence studies from mainland China, Hong Kong and Taiwan between 1980 and 2012, the total number of people aged 60 and over with dementia in mainland China, Hong Kong and Taiwan is 8.4 million and in northern, central and southern areas are 3.8, 3.2 and 1.2 million respectively (Wu, 2013).

1.5 The challenges caused by dementia

Dementia is a disorder that damages the brain cells, associated with a decline in memory or other thinking skills severe enough to reduce a person's ability to perform everyday activities. It is a biomedical, psychological and societal disability, which poses complex challenges that are different to those of many other disabilities. The ageing of the population means that the number of people with dementia will grow in future decades with consequent implications for care provision, care burden and public expenditure (Cahill, O'Shea, 2012). As a global health problem, it takes a heavy toll on people, society and the economy. (Bloom, 2011).The estimated cost of formal and informal care for dementia worldwide is currently in excess of 600 billion dollars accounting for 1% of the world's gross domestic product(Cahill, 2012). Dementia is the third most expensive disease to treat in the world after cancer and heart disease. The cost estimates for dementia in the UK, ranging from £ 1 billion to over £ 14 billion per year.

1.6 The care givers for people with dementia

Today, dementias account for at least 40% and, by some estimates, up to 60% of nursing home admissions (Hussein, 2012). People with dementia, therefore, become increasingly reliant on family, friends and neighbours, as well as health and social care services. Care givers (usually relatives but sometimes friends and neighbours) provide the majority of such care. Carer stress is common, with approximately 30% of care givers having significant psychiatric morbidity (Donaldson *et al.*, 1997). Despite much public education over the last 2 decades, dementia remains a stigmatizing illness, causing difficulties for both people with dementia and care givers.

The main social services for people with dementia is Long-term care (LTC), that is, ongoing services and supports for people with chronic and disabling conditions who require assistance with activities of daily living such as bathing and eating. There are different kinds of long-term care. According to the service demand, there are health care and social care; in terms of service place, are institutional care and domiciliary care; in consideration of care-giver, formal care versus informal care. So called 'informal care', provided with financial compensation by family and friends to people with dementia, plays a crucial role in mediating the impact of need on the demand for formal care services (Davies *et al.*, 2000; Van Houtven *et al.*, 2004). In fact, approximately 95% elderly people living in family in the US, and only 2% British senior citizens living in the long-term care institutes. It is estimated that informal care share 80% part of elderly care in developed countries (Wei, 2012). A survey conducted in the UK, showed that most people with dementia are able to live in their own homes for most of their lives, and most care is given by families. Between 36% and 53% of people with mild to moderate dementia live in the

community, and 35% of those with high-level needs live at home supported by carers (Melzer *et al.*, 1997; Parsons, 2001).

In China, aged patients account for 60% of emergency cases, 49% of hospital days, and 85% of long-term care beds. Among the elderly aged 65–74 years, 26% have a low-quality life due to chronic diseases. Among those aged over 75 years, two thirds suffer from three or more chronic diseases, nearly half have one or more functional disability (DH, 2001; Flaherty *et al.*, 2007). However, there is no specially adapted healthcare system for the elderly, especially for the people with dementia. Aged people have to visit general hospitals, no matter how serious or mild the disease is, and they follow the same procedures as other adult patients. Additionally, the importance of post-acute, rehabilitation, long-term care, and hospice care has not yet received sufficient consideration.

2 Non-pharmacologic Interventions

2.1 The role of non-pharmacologic interventions for dementia

Dementia may be caused by irreversible as well as treatable causes. Most cases of dementia tend to progress unless the underlying cause is treatable and reversible. Currently, drug and non-drug treatments may help with both cognitive and non-cognitive symptoms. Researchers are looking for new treatments to alter the course of the disease and improve the quality of life for people with dementia. Because most forms of dementia cannot be cured, the aim of treatment is to delay disease progression and to maintain functioning and quality of life. (Suzuki *et al.*, 2006)

Due to concerns about side effects from drugs for dementia many people in the world have been searching for natural remedies to prevent and treat this problem. Along with pharmacological treatment, various non-pharmacological interventions have been applied in the management of behavioural, psychosocial and cognitive symptoms of people suffering from dementia. Non-pharmacologic interventions approach aims at addressing the psychosocial/environmental underlying reason for the behaviour and avoids the limitations of pharmacological interventions, such as adverse side effects, drug–drug interactions, and limited efficacy (Cohen-Mansfield et al., 1999; Schneider, 1996). Besides, medication may mask the actual need of the people with dementia so as to reduce the already-compromised communication with caregivers. Non-pharmacological approaches have shown benefits as regards alleviating behavioural symptoms (agitation, aggression), slowing the progression of cognitive dysfunction, preserving independence in everyday activities, and improving the overall quality of life.

Non-pharmacological approaches to the care of people with dementia differ from pharmacological treatment in that they consider the interaction between the person, caregiver, environment, and system of care in the treatment design. Such interventions generally provide more personalized care for these individuals, addressing their needs, and considering their preferences. Non-pharmacological interventions have been used to enhance cognition, affection, and performance of activities of daily living; to reinforce a positive sense of self; and to reduce agitation/behaviour problems and psychotic symptoms. (Cohen-Mansfield, 2005.)

2.2 The classification of non-pharmacological interventions

The main therapeutic goal to treat dementia highlighted with two major domains: cognitive symptom and non-cognitive symptom. Each of the areas has the aim of improving the quality of life and well-being of people with dementia, which may in turn impact on the well-being of those providing care. Cognitive symptoms are, of course, recognized as the core of any definition of dementia, and interventions targeting them have been the subject of much research and interest. However, the link between improving cognitive symptoms and maintaining day-to-day function is also the key point. Non-cognitive symptoms often experienced by people with dementia that are sometimes described as neuropsychiatric symptoms or ‘behavioural and psychological symptoms of dementia’ (BPSD), which include delusions, hallucinations, depression, anxiety, apathy and a range of behaviours, such as aggression, wandering, disinhibition and agitation.

Some popular non-pharmacological interventions are discussed in the frame of two main approaches: cognitive approaches, multi-strategy approaches (reality orientation, reminiscence therapy and validation therapy), and miscellaneous approaches (Table 2-1).

Table 2-1. Non-pharmacological intervention to Alzheimer patients			
Therapy	Cognitive	ADL	BPSD
Cognitive training	+	+	+
Cognitive rehabilitation	+	+	+

Cognitive stimulation therapy	+	+	+
Snorezen/multisensory stimulation	+	+	+
Reality orientation	+	+	+
Reminiscence therapy	+	-	+
Validation therapy	+	-	+
Physical activity	+	+	+
Light therapy	+	-	+
Music therapy	+	-	+
Aromatherapy	-	-	+
Animal-assisted therapy	-	-	+

Notes: ADL, activities of daily living; BPSD, behavioural and psychological symptoms of dementia.

Three major types of approach with a cognitive focus have been delineated (Clare & Woods, 2004). These are:

(1) Cognitive stimulation, which entails exposure to and engagement with activities and materials involving some degree of cognitive processing, usually within a social context and often group based, with the emphasis on enjoyment of activities.

(2) Cognitive training, which involves specific training exercises geared to specific cognitive functions. It includes practice and repetition, may be computer-assisted and may be individual or group based.

(3) Cognitive rehabilitation, which is always individually tailored, involving working on personal goals, often using external cognitive aids and with some use of learning strategies; it is carefully targeted.

However, the APA (American Psychiatric Association , APA) Practice Guidelines for the Treatment of People With Alzheimer's Disease and Other Dementias reviewed literature for the period January 2003 to December 2006 and concluded that non-pharmacological psychosocial treatments for dementia can be divided into four broad groups: behaviour-oriented, emotion-oriented, cognition- oriented, and stimulation- oriented (Table 2-2) .

Table 2-2 non-pharmacological psychosocial treatments for people with dementia

Treatment orientation	Therapy
Cognitive-oriented Treatments	Reality orientation,

	Cognitive stimulation therapy
	Cognitive behaviour therapy
Behaviour-oriented Treatments	Light therapy
	Behaviour therapy
	Behavioural management therapy
Stimulation-oriented Treatments	Music therapy,
	Physical activity ,
	Aromatherapy,
	Multisensory stimulation,
	Art therapy
Emotion-oriented Treatments	Reminiscence therapy,
	validation therapy,
	Supportive psychotherapy
	sensory integration,
	Simulated presence therapy.

2.3 The common psychological interventions

Psychological therapies are a group of treatment methods that involve psychosocial rather than physical intervention. They include cognitive behavioural therapy, family therapy, systemic family therapy, non-directive supportive therapy, psychodynamic, psychotherapy, group psychotherapy, counselling, art therapy, interpersonal psychotherapy, guided self-help and any other form of therapy that aims to be helpful through the communication of thoughts and feelings in the presence of a therapist, who works with the material using a systematic framework for understanding and responding to it (Rabins, 2007).

(1) Cognitive behavioural therapies (CBT):

Where there is significant cognitive impairment of people with dementia, non-pharmacological interventions for mood disorders are necessary. Cognitive behavioural therapies, a range of behavioural and cognitive behavioural therapies, in part derived from the cognitive behavioural model of affective disorders, in which the people with dementia works collaboratively with a therapist using a shared formulation to achieve specific treatment goals. Such goals may include recognizing the impact of behavioural and/or thinking patterns on feeling states and encouraging alternative cognitive and/or behavioural coping skills to reduce the severity of target symptoms and problems (Rabins, 2007).

Cognitive behavioural therapy is a recognised treatment for depression and anxiety in general use. CBT may be used in outpatient or other community settings in the early stages of dementia and delivered by appropriately trained nurses or other mental health professionals, individually or in groups (Scholey & Woods, 2003; Kipling et al., 1999).

Although there is a wide evidence base for the use of CBT in the general population without dementia, there has been very little work specifically focusing on its use in emotional disorders associated with dementia. Most research described behavioural approaches and has required positive outcome on the mood of the carer as well as the people with dementia, although tend not to be in relation to the severity or staging of dementia. It is therefore difficult to assess the effectiveness of CBT and related approaches in

different stages of dementia. Evaluation of the treatment was hampered by an overall lack of controlled randomised studies, despite their widespread use in some cases.

(2) Cognitive Stimulation Therapy (CST)

There is a growing interest in psychosocial interventions in dementia care in past two decades. Psychological interventions have been implemented for people with dementia since nearly 50 years ago. Initially, psychosocial interventions for dementia have frequently been developed without a clear theoretical framework or proper consideration of the evidence from research or clinical practices. Few have reached the stage of rigorous evaluation and even fewer have been widely implemented. The need for a rapid increase in the quantity and quality of psychosocial research in dementia care has been more urgent. On this occasion, the development of group Cognitive Stimulation Therapy (CST) has extended beyond family care.

Clare and Woods (2004) provided a definition which stated that cognitive stimulation: (a) targets cognitive and/or social function, (b) has a social element—usually in a group or with a family care-giver, (c) includes cognitive activities which do not primarily consist of practice on specific cognitive modalities, and (d) may be described as reality orientation sessions or classes.

The first randomised controlled trial (RCT) to describe intervention as cognitive stimulation evaluated a 5-week group programme which relied on mental imagery and stimulated various perceptual modalities, with tasks including word association and object categorisation (Breuil et al., 1994). A total of 201

people with dementia were recruited for this single-blind, multi-centre RCT from 23 day centres and residential homes in London. (Spector, 2000). Another study used a 14-session, 7-week themed programme including topics such as word association, object categorisation, discussion of current affairs and orientation. It creatively incorporated principles of good practice in order to aid learning, such as implicit learning rather than explicit teaching and focusing on opinion rather than fact (Spector et al., 2003).

In the UK, group CST is now recommended in evidence-based practice guidelines (NICE–SCIE Guideline for the management of dementia in the UK, www.nice.org.uk). CST used in Chinese people with dementia was reported 5 years ago, but rarely have they been standardized, adequately evaluated or systematically implemented (National Collaborating Centre for Mental Health, 2007).

Feedback from the previous CST studies (Spector et al., 2003) suggested that service users preferred a longer-term programme after the seven-week CST intervention. The pilot study of maintenance CST (Orrell, Spector, Thorgrimsen & Woods, 2005), following the initial CST programme, offering 16 weekly sessions of maintenance, lasting nearly 6 months in comparison to a group of CST only, found a significant improvement in cognitive function. Two RCTs found that over 6 months, cognitive stimulation and cholinesterase inhibitors in combination, were more effective than cholinesterase inhibitors alone (Olazarán et al., 2004; Onder et al., 2005).

(3) Intervention for communication

Inappropriate behaviour, defined as “inappropriate verbal, vocal, or motor activity that is not judged by an outside observer to be an obvious outcome of the needs or confusion of the individual.”(Cohen et al., 1984), are very common in dementia and increase suffering for the people with dementia and burden for caregivers. Thus, Communication from people with dementia is often discounted as unreliable or disordered, and therefore needs expressed by people with dementia often go unmet, resulting in need-driven behaviour. (Kovach, Noonan, Schlidt, & Wells, 2005).However, a study showed that disruptive behaviours decreased 56% during social interaction, and the researchers concluded that sensory deprivation and social isolation may evoke underlying emotions of fear, loneliness, and boredom that may lead to disruptive behaviours (Cohen-Mansfield & Werner,1997). Kitwood (1988) described successful social communication with people with dementia as collaborative and maintained that such communication increases self-esteem, a sense of purpose, social confidence, and hope in the people with dementia. Acton (1999) has demonstrated that individuals with dementia are able to transmit meaningful communication and this communication can be interpreted by others, making client-centered interventions possible with this population.

From 1980-2011, there are some qualitative research studies and controlled intervention studies on communication that included institutionalized people with dementia and/or care staff studies. Armstrong and Woodgate (1996) recorded the conversation of people with dementia and found that theme-related discussions and structured activity increased the amount of communication. In 1988, Sandman, Norberg, and Adolfsson observed and

video recorded the communication of five institutionalized people with dementia during meals, indicating that caregivers can unintentionally influence the communication efforts of people with dementia in a negative manner. Small and Perry (2005) examined the types of questions spouse caregivers used to communicate with their care receivers, more successful communication resulted with the use of yes-no questions or questions required semantic memory. Muller and Guendouzi (2005) concluded that the dynamic nature of communication with people with dementia requires equally dynamic strategies. Camp, Cohen-Mansfield(2005) stress the need to individualize interventions to meet the needs of people with dementia. Besides, a walking programme combined with conversation (Friedman & Tappen, 1991; Cott et al., 2002; Tappen et al., 2002), group validation therapy (Toseland et al., 1997; Tondi et al., 2007), life review programmes (Tabourne, 1995; Haight et al., 2006), cognitive stimulation therapy (Spector et al., 2003; Orrell et al., 2005), and activity therapy (Politis et al., 2004) are effective set-time interventions. A series of daily-care intervention studies consisted of training programmes aimed solely at teaching care staff communication techniques (McCallion et al., 1999; Dijkstra et al., 2002; Magai et al., 2002; Finnema et al., 2005; van Weert et al., 2006) or multi-component training or educational programmes that also included communication techniques (Edberg and Hallberg, 1996; 2001; Wells et al., 2000; Beck et al., 2002; Burgio et al., 2002). As well as using verbal and body language, communication may need to take written or pictorial form (Oddy, 2003), such as memory books. Memory books consist of individualised images and simple statements that the people with dementia and care givers can use to aid the individual's recall and the quality and frequency of communication (Bourgeois et al., 2001).

According to the communicating M-C-R model (Berlo,1960), a literature map (see Figure2-2, Figure2-3) was developed and tried to describe the impact to communication by above interventions .

(4) Creative expression intervention

Recently, researchers, practitioners, and policy makers have expressed interest in using creative expression (CE) programmes to improve the communication and quality of care of people with dementia in long-term care (LTC) settings (Bernfeld & Fritsch, 2006 ; National Institute on Ageing,2006). Fritsch, Kwak, Lang, Montgomery, and Basting (2009) published the results of an RCT that compared 10 nursing homes for Creative Expression Programme with 10 control nursing homes. Time sampling was used to observe resident engagement and affect across different types of activities, although not specifically during creative expression programme sessions. Researchers found significant improvement in resident general alertness, resident engagement, quantity and quality of staff-initiated interactions, and staffs attitudes toward people with dementia in treatment homes compared with control homes. Another study, published in 2010, suggests that CE storytelling sessions improve the affect and communication skills of people with dementia (Phillips, 2010). George (2011) evaluated whether medical student participation in Creative Expression Programme with people affected by dementia would improve student attitudes toward the people with dementia through a qualitative research. Creative expression programme has been shown to be effective for engagement of both people with dementia and carers to communicate in the USA.

Overall , Positive effects for communication outcomes are shown in individual studies when set-time interventions are single-task sessions. They illustrated that care staff can improve their communication with people with dementia when strategies are embedded in daily care activities and that staff training should include time for personal feedback, interactive learning and refresher sessions.

TimeSlips was developed by Anne Davis Basting, the director of the Center on Age & Community at the University of Wisconsin Milwaukee, whose work focuses on the potential for the arts and humanities to improve our quality of life for people with dementia. TimeSlips is a creative storytelling method that opens storytelling to everyone by replacing the pressure to remember with encouragement to imagine. It was originally designed as a way for people with dementia and their care partners to share in creative expression together. Since its inception in 1998, TimeSlips has become a way for people to grow and connect across the challenges of cognitive disability. That originally designed to support growth and learning with people with dementia and their caregivers, the Time Slips method is fun for anyone. This project aims to Inspire people with dementia to share the gifts of their imaginations ; Inspire others to see beyond loss to recognize the strengths of people with dementia ; Improve the quality of life of people with dementia and those who care for them (George, 2011).

The main difference of TimeSlips with other non-drug therapy is: TimeSlips encourages people with dementia to express themselves with language, action, pictures, etc. They concerned about their social role instead of patient role itself. They believe that people with dementia could built up relationship with others and develop at any stage. Besides, TimeSlips is based on creative ability instead of memory so that the participants would have few frustrate feeling due to the impairment of cognition.

There is some research telling us that creative engagement has significant impact on the lives of people with dementia(Fritsch et al., 2009). To assess the potential benefits of TimeSlips, a purposeful sampling strategy employed seeking to select long-time caregivers of nursing homes and hospitals, data were collected pre- and post-intervention, as well as at a mid-point of the intervention. In addition, the socialization encouraged by the group format, and the creative, collaborative storytelling task of the TimeSlips intervention, lead to improved psychological well-being as indexed by measures of psychological symptoms and quality of life. This one suggests that Time Slips improves the quantity and quality of engagement between staff and residents on dementia units, even among those who didn't take the training or participate in the sessions. It also improved the attitudes of the staff toward people with dementia (Lorraine, 2010).

From the communicating model (Figure 2-3), it has been shown that CE programme may influence both encoder and decoder through certain fixed characteristics, such as culture, communicating skill, social system, attitude. CE programmes stimulated participants to become and stay engaged and

increase positive mood and communicating skill of people with dementia; For staffs, it has been revealed that the CE programmes encouraged the development of positive attitudes toward people with dementia. Creative expression programmes are based on the philosophy of “person-centred ” care, and serve as a conduit for staffs to learn about the inherent value and dignity of the people with dementia. With more positive attitudes staffs initiated more and better interactions with residents. The increasingly frequent staffs- and people with dementia -initiated interactions will encourage and reinforce more exchanges between both groups over time.

TimeSlips began to be used in the world except Chinese people with dementia, however, rarely have they been standardised, adequately evaluated or systematically implemented. It is worth to explore what is the proper CE in Chinese people with dementia and to evaluate the potential benefits of effects of TimeSlips intervention on communication, cognitive competence and quality of life in people with dementia in China.

(5) Other common psychological interventions

There are a wide range of psychological interventions currently provided in the world for people with dementia, but their availability varies greatly. In the early stages of dementia, individual psychological treatment or group activities may focus on improving memory, adjustment and mood, using cognitive behavioural therapy (CBT) (Scholey & Woods, 2003; Cheston et al., 2003a; Kipling et al., 1999) or life review, cognitive rehabilitation approach (Clare, 2003).

In the late stages of dementia, sensory stimulation is the primary form of psychological intervention. The aim is often to provide relaxing stimulation and to reduce agitation and distress. Thus group activities interventions are appropriately used for people in the later stages, including cognitive stimulation, reminiscence, music, and arts and crafts (Spector et al., 2003; Holden & Woods, 1995; Gibson, 2004). There have been a series of psychological interventions proved to be effective to the people with dementia as following:

Reminiscence: Involves the discussion of past activities, events and experiences, usually with the aid of tangible prompts (for example, photographs, household and other familiar items from the past, music and archive sound recordings). Reminiscence therapy in a group context has the aim of enhancing interaction in an enjoyable, engaging fashion (Woods et al., 1992).

Validation therapy: Based on the general principle of validation, the acceptance of the reality and personal truth of another's experience, validation therapy incorporates a range of specific techniques. Validation, in this general sense, can be considered as a kind of philosophy of care. It is identified as providing a high degree of empathy and an attempt to understand a person's entire frame of reference, however disturbed that might be. Important features of validation therapy are said to include: a means of classifying behaviours; provision of simple, practical techniques that help restore dignity; prevention of deterioration into a vegetative state; provision of an emphatic listener; respect and empathy for older adults with Alzheimer's-type dementia, who are struggling to resolve unfinished business before they die; and acceptance of

the person's reality. These features are not, however, unique to validation (Neal & Barton Wright, 2003).

Relaxation therapy: Relaxation therapy uses a variety of physical and mental techniques (for example, tensing and relaxing different muscle groups in turn, imagining peaceful scenes, and so on) to help people to reduce bodily and psychological tension in a systematic way, which they can practice at home and use when under stress. It can be used as a component of a treatment package (for example, behaviour therapy) or as a therapy in its own right.

Life review: A naturally occurring process where the person looks back on their life and reflects on past experiences, including unresolved difficulties and conflicts. This concept was incorporated in the psychotherapy for older people, which emphasises that life review can be helpful in promoting a sense of integrity and adjustment. Life--review therapy has its roots in psychotherapy, involving evaluation of personal (sometimes painful) memories with a therapeutic listener, usually in a one-to-one setting (Woods et al., 1992).

Snoezelen: Provides sensory stimuli to stimulate the primary senses of sight, hearing, touch, taste and smell through the use of lighting effects, tactile surfaces, massage, meditative music and the odour of relaxing essential oils (Chung et al., 2002).

Animal-assisted therapy: The use of trained animals in facilitating people with dementia progress toward therapeutic goals (Barker & Dawson, 1998).

Training and support are needed for care givers to be able to put these approaches into practice. Moreover, interventions need to be geared to the different stages of the care-giving career, with particular issues arising for those care givers. As behavioural approaches aim to help finding the problem and responding to the difficulty, with regard to the difficult behaviour, the approach can be flexibly modified by the care givers (Moniz-Cook et al., 2003). Psychological interventions include individual psychological treatment for depression and anxiety in the significant proportion of carers (Marriott et al., 2000). Groups for family care givers are widely available and encompass a broad range of models of intervention (Pusey & Richards, 2001).

Those studies aimed to brain-activating rehabilitation are to enhance people with dementia motivation and maximize the use of their remaining function, recruiting a compensatory network, and preventing the disuse of brain function. The primary effects are that people with dementia recover a desire for life, as well as their self-respect. Enhanced motivation can lead to improvements in cognitive function. Due to the renewed positive attitude towards life, the behavioural and psychological symptoms of dementia and activities of daily living improved. In addition, improvements in the quality of life for both people with dementia and caregivers were accompanying outcomes. Nevertheless, few of these treatments have been subjected to rigorous double-blind, randomized, controlled trials, although some are supported by research findings and have gained clinical acceptance. Published studies have generally been based on small samples and have been of limited duration, and many of the reports fail to fully characterize the intervention, the nature or stage of the subjects' dementia, their baseline status, or the persistence of any

improvement.

2.4 The philosophy of the non-pharmacological interventions

(1) Patient- centred care

The principles of person-centred care, as set out by Kitwood (1997) have achieved a broad consensus of support in dementia care in the world. Tom Kitwood was the most influential leader of the philosophy toward person-centered care for people with dementia, who advocated person-centered dementia care as acknowledging that the individual is a person that can experience life and relationships, despite the progressive disease, offering and respecting choices. including the person's past life and history in their care, focusing on what the person can do, rather than the abilities that have been lost owing to the disease (*The Person Comes First*) (Basting, 2011). In person-centered care, the focus of the care is "centered" on the whole person, not just their symptoms or diagnosis. Some people prefer the term "person-directed" care, which means that the person receiving care directs the choices in their own care (Basting, 2011). People who practice person-centered care should regard personhood in people with dementia as increasingly concealed rather than lost, acknowledge the personhood of people with dementia in all aspects of care, personalize care and surroundings, offer shared decision-making, interpret behaviour from the person's viewpoint, prioritize relationships to the same extent as the care tasks(*Edvardsson et al. 2008*).

(2) Social care model

Marshall has advocated that dementia should be regarded as a disability and

framed within a social model. In the social model, it is primary to understand disability not as an intrinsic characteristic of the individual, but as an outcome not at the level of personal psychology, but is a condition created by a combination of social and material factors including income and financial support, employment, housing, transport and the built environment (Barnes *et al.*, 1999). In terms of people with dementia, the social model believes that the disability is not the 'fault' of the individual, who can be fully understood. The care givers should focus on the skills and capacities the person retains rather than loses, endorsed of appropriate communication, develop an enabling or supportive environment, take opportunities for rehabilitation (Gilliard *et al.*, 2005). Moreover, a variety of aspects of care may affect a person as the dementia.

A. Respecting

Respect for autonomy is recognised as a key principle in health and social care (Beauchamp & Childress, 2001). Many ethical problems that arise in looking after people with dementia emerged due to the requirement that autonomy ought to be respected. Person-centred care is a way of respecting personal autonomy (Kitwood, 1997). Autonomy fundamentally involves the way individuals live their daily lives and experience (Agich, 2003). Thus respecting autonomy exist in day-to-day interactions and good-quality communication (Kitwood, 1997; Sabat, 2001).

B. Consent

Consent is not solely an issue as regards medical procedures. Consent must comprise the following elements: informed, competent, uncoerced, continuing.

All aspects of life to which the person with dementia may or may not wish to consent, like what to wear or to eat, whether to go out or participate in an activity and whether to accept extra home or respite care. If people with dementia has capacity of special decision, but does not wish to consent, he or she should be supported in making an autonomous decision (Agich, 2003).

C. confidentiality

People with dementia have a right to expect that information given in confidence to professionals will be kept confidential. The issue of confidentiality in dementia care manifests that to maintain balance between respecting the person's autonomy and recognising the complex ways in which people in a society are mutually dependent and inter-related (Hughes & Louw, 2002).

3 Evaluating tools of dementia care

Researchers have developed a series of tools with high reliability and validity to evaluate the outcomes of dementia care, by means of which the previous clinical trials showed that non-pharmacological intervention led to significant benefits in both cognition and quality of life, as well as a trend towards an improvement in communication and it was found to be cost effective.

3.1 Cognitive function

Cognition is usually measured using the ADAS-Cog (Rosen, Mohs & Davis, 1984). The ADAS-Cog consists of 11 tasks measuring the disturbances of memory, language, praxis, attention and other cognitive abilities which are often referred to as the core symptoms of AD. In addition, a brief Mini-Mental

State Examination(MMSE) is also widely used to test cognitive function with good reliability and validity(Folstein, Folstein & McHugh, 1975)

3.2 The quality of life

There are various tools to measure quality of life for deferent health problem. However, those tools are generally adapted and suitable for people with dementia and their carers. Firstly, Quality of Life--Alzheimer's disease Scale(Logsdon et al.,2002) covers 13 domains of quality of life. It has good internal consistency, validity and reliability and is recommended by the European consensus on outcome measures for psychosocial interventions in dementia(Moniz-Cook et al., 2008). Secondly, the EQ-5D (Euro QoL Group,1990) is a standardised instrument for use as a measure of health-related quality of life. It contains a 3-level coding system for 5 dimensions. The instrument includes a global rating of current health using a visual analog scale. Last but not least, the DEMQOL (Smith et al.,2005) uses self-rated reports of QoL administered by a trained interviewer. There is also a separate scale for family caregiver or members of staff reports, the DEMQOL-proxy. It includes 5 domains of quality of life. The DEMQOL has high internal consistency and acceptable inter-rater reliability.

3.3 Communicating ability

Communication is assessed using the *Holden Communication Scale* (Holden & Woods ,1995). This scale is completed by staff or family caregivers and covers a range of social behaviour and communication variables. The Functional Assessment of Communication Skills (FACS), available from the American Speech-Language-Hearing Association, scores communicative

impairments in daily life. It contains 43 items divided into four communication domains: Social Communication, Communication of Basic Needs, Reading, Writing and Number Concepts, and Daily Planning.

3.4 Mood

Cornell Scale for Depression in Dementia rates depression in five broad categories using information from interviews with staff and participants. Good reliability and validity have been demonstrated (Alexopoulos et al., 1988).

Anxiety is assessed using the *Rating Anxiety in Dementia scale* (Shankar et al., 1999). This rates anxiety in four main categories and uses interviews with staff and participants. It has good validity and reliability.

3.5 Behaviour

Behaviour is assessed using the *Neuropsychiatric Inventory* (NPI) (Cummings et al., 1994). The NPI assesses 10 behavioural disturbances occurring in people with dementia. Studies report that it has good validity and reliability.

Activities of daily living are assessed using the *Alzheimer's Disease Co-operative Study - Activities of Daily Living Inventory* (ADCS-ADL) (Galasko et al., 1997) The ADCSADL is a structured questionnaire originally created to assess functional capacity over the range of dementia severity. The sensitivity and reliability have been established.

3.6 Pressure of care givers

Family Caregiver health is assessed using the *Short Form-12 Health Survey* (SF-12) (Ware, Kosinski & Keller, 1996). This scale measures generic health concepts relevant across age, disease, and treatment groups. The SF-12

includes 8 concepts commonly represented in health surveys. It is a self-administrative measure that provides a comprehensive, psychometrically sound, and efficient way to measure health from the people with dementia point of view by scoring standardized responses to standard questions.

3.7 Economic evaluation

Cost-effectiveness analysis: A type of full economic evaluation that compares competing alternatives of which the costs and consequences vary. The outcomes are measured in the same non-monetary (natural) unit. It expresses the result in the form of an incremental (or average or marginal) cost-effectiveness ratio (Rabins et al, 2007).

Client Services Receipt Inventory (CSRI) (Beecham & Knapp 1992) is usually adapted to evaluate cost in studies of mental health and dementia, which gathers comprehensive data on accommodation, medication and services received.

4 Limitations of existing knowledge

The results of the literature review show that the field needs to be expanded in a number of ways in order to have clinical usefulness as below:

(1) Methodological weaknesses were common in most of the research projects .Firstly, the methodological quality of the studies was generally poor, taking some outcome measures that were used for communication as an example, the reliability and validity were questionable. Secondly, the issue of

individualisation and proper selection of treatment opportunity time existed. Thirdly, the issue of costs, what would be lower-cost interventions comparable in effectiveness to higher-cost interventions? Lastly, system change, what changes in staffing roles and structure and ongoing feedback mechanisms are needed to translate the research from efficacy to practice?

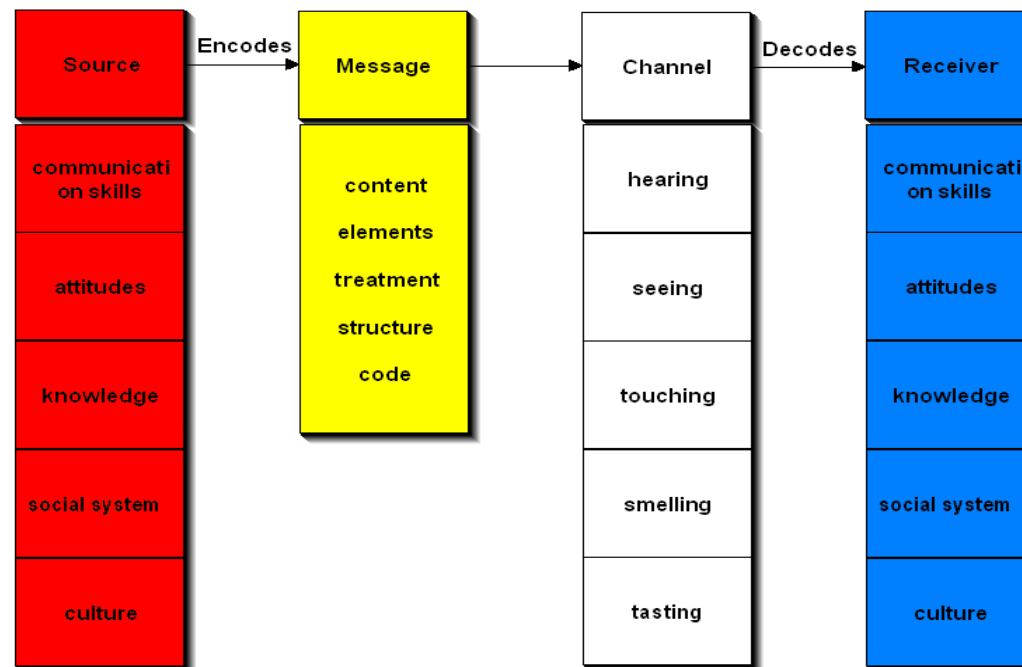
(2) Basing on communication model, there is some space needed to study such as attitude, culture, social, etc. Message may have different meanings associated with it depending upon the culture or society. However, there are limited cross-cultural studies of behavioural and psychological treatment on dementia.

(3) In terms of creative expression programme, more studies are needed to better understand the mechanisms by which creative expression programme improves both staff and resident outcomes. The former studies used a time-sampling method, a post-only study design, but not prior to the intervention, not examining patterns of change over time. Future research is needed to examine how changes in resident outcomes occur over time.

(4) Studies are needed to compare structures, processes, and outcomes across countries with similar demographics and health systems to improve models of service delivery. Research is needed to translate and implement what been achieved in one country to the cultures and contexts of other nations. Taking China as an example, there are relatively few nursing and elderly care homes as compared with Western countries. There is a strong obligation to care for dependent older family member that is influenced by

cultural beliefs and filial responsibility, particularly among Chinese people with traditional beliefs and values in Confucianism. Most family care-givers are lack of special training. It is worth to explore what is the proper TimeSlips in Chinese people with dementia and how cost- effective its implementation in China.

Berlo's Model of Communication



A Source encodes a message for a channel to a receiver who decodes the message:
S-M-C-R Model.

Figure 2-2 S-M-C-R Model

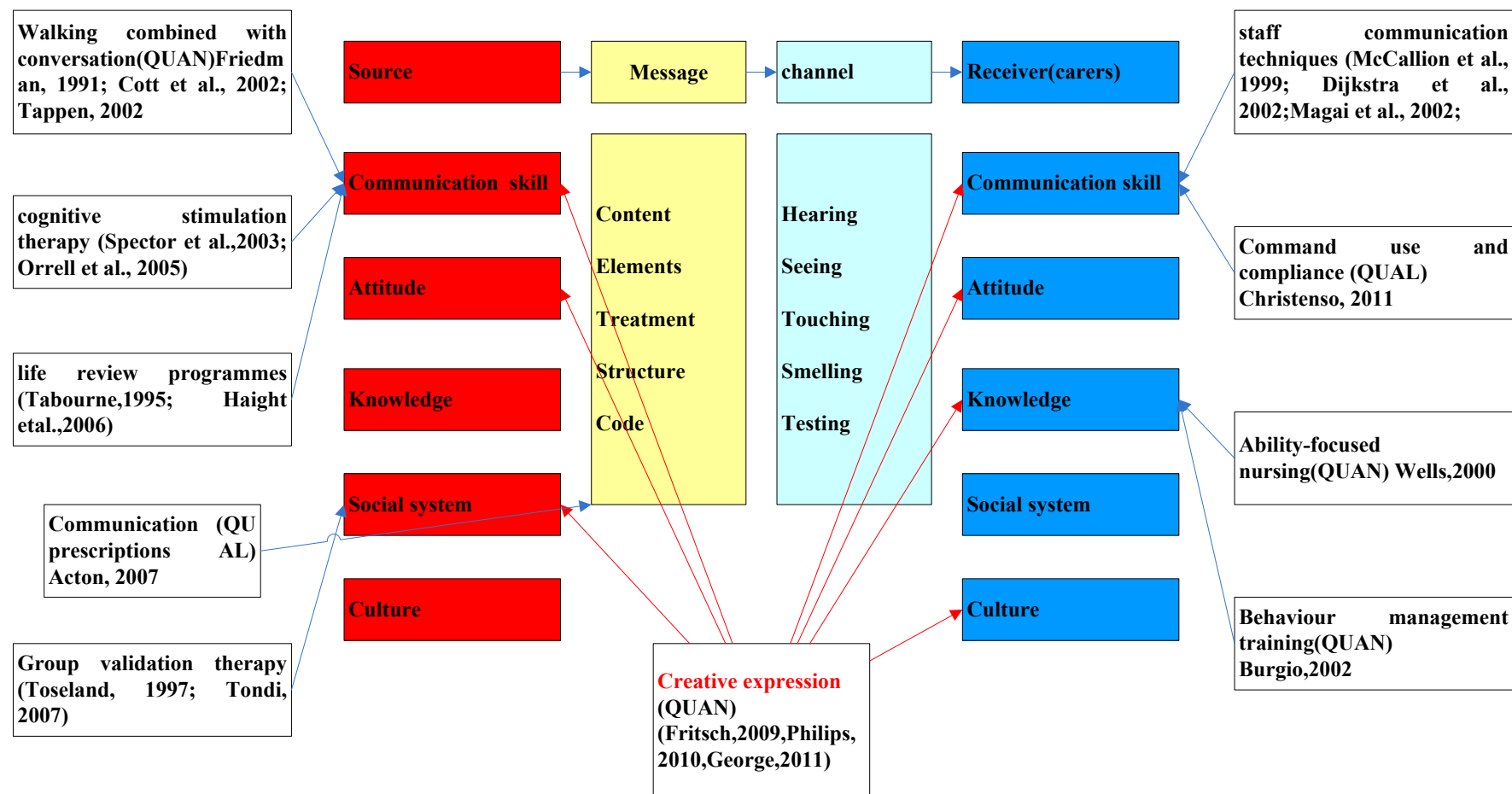


Figure 2-3 S-M-C-R Model

Chapter 3: Overall Methodologies and Study Design

1 Research Question

(1) How could caregivers give a standard creative expression intervention suitable to Chinese people with dementia ?

(2) Could creative expression intervention impact Chinese people with dementia as well as carers ?

2 Aim of Research

The aim of this study was to create an evidence-based creative expression therapy programme for Chinese people with dementia and assess its outcome on the care of people with dementia.

3 Objectives of Research

3.1 To develop the practice-based creative expression intervention for Chinese people.

3.2 To implement the developed creative expression intervention for Fuzhou people with dementia in hospitals and rest-homes for 6 weeks.

3.3 To evaluate the effectiveness of the interventions for Fuzhou dementia people on their quality of life, ability of communication and daily life.

4 Study design

The overall research strategy was mixed method, employing the combination of both qualitative and quantitative approaches. A sequential exploratory mixed method was adopted in this study. The procedures were those in which the research seeks to elaborate or expand on the findings of one method with another, involving a first phase of qualitative data collection and analysis, followed by a second phase of quantitative data collection and analysis.

The focus attention of the study was on the exploration an appropriate behavioural therapy for people with dementia. Mere positivist approach does not provide the means to examine people with dementia and their behaviours in an in-depth way. The exploration and examination of human behaviours such as attitude and feelings are beyond the scope of positivism. Qualitative research, a post-positivist approach, may help us explore the different factors to stimulate creative expression under different culture. And also, action research as one kind of qualitative method, used to develop a standard intervention within a continuing improvement health practice process, has been proved to be an effective research method. In this study we employed an action research to develop a creative expression practice model for Chinese people with dementia. This action research combined qualitative techniques, as observation and semi-structure interviewing, with pilot quantitative measurement of cognitive function and quality of life. Overall, the action research was undertook 3 sessions on totally 31 cases of people with dementia from the geriatric wards, long term care institution and their homes for 7 rounds following the process of plan-action-observe-rethinking cycle.

On the other hand, most previous study, the positivist approach to evaluate the interventions effects embraces a philosophy in which verifiable statements concur with the ascertainable facts of reality. The outcome of intervention can be verified through comprehensive evaluating tools with high reliability and validity. After a preliminary studies, such as investigating the LTC settings , small sample of pre- and post- comparison of the effectiveness, converting FAS tools into Chinese, the quantitative study was designed and conducted as control rigorously as far as possible, we believe the study answered the question whether creative expression programme is beneficial for Chinese people with dementia. (figure 3-1)

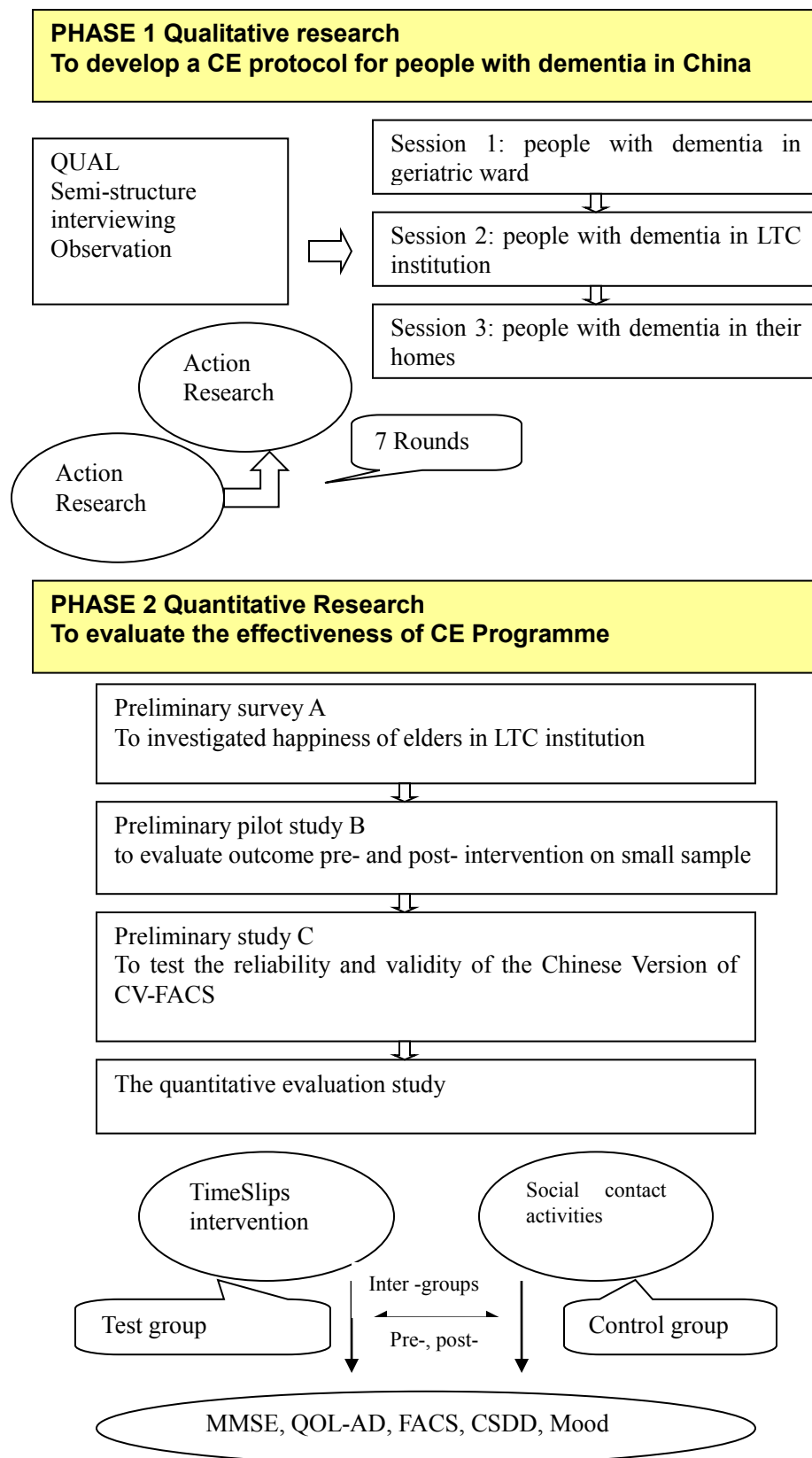


Figure 3-1 The research flow chart

5 Research ethics

5.1 Consideration of people with dementia:

The benefits would be shown in improvements in mood and engagement in participants, and the increased interactions between staff and participants. Moreover, as many CE programmes are implemented for at least several weeks in each facility, it is possible to see spill over effects across participants and staff. That is, as staff members adopt person-centered attitudes, they will serve as models for other staff who did not directly participate in the CE sessions through observational learning. Besides, this study was anticipated to develop a standard of behaviour intervention and nursing practice on Chinese dementia people and it would add trans-cultural evidence on dementia treatment.

One of the main ethical issues is how to deal with informed consent to participate in the study for these people affected by dementia. Firstly, the cognitive complementary was assessed to judge whether participants had capacity to give consent by themselves. Written consent was sought from mild patients and permitted by their family. For those moderate level patients, the consent was signed by their families after permitted by the participants. However, the severe level dementia patients were eliminated in this study. The consent was an on-going process and actually in this study there were 4 participants and their families unwillingly continue to receiving intervention and withdraw during the course of the research process. A copy of the information consent form is included in the Appendices II.

To ensure the treatment pathway innocuousness, we have combined qualitative observation with literature review and experts discussion to explore a feasible practice standard. In addition, the intervention itself is non-invasive, non-pharmacy and painless. We routinely collected evaluating data which will be anonymous and access restricted to the investigators.

5.2 Consideration of care-givers:

All participants, families or care-givers in hospital and care homes will be informed about the programme and on a voluntary basis. They should be informed of the purpose of the study and what would be expected of them as participants, guaranteed confidentiality of their personal identity and data collected and It made clear to participants and family care-givers that no disadvantage would occur wherever possible a family member or other choose not to participate. Many "ethical conflicts" in medical ethics always could trace back to a lack of communication. We hope apparently insurmountable "ethics" problems can be solved with open lines of communication.

The study has been obtained permission from the Human Subjects Ethics Committee of Fujian Provincial Hospital (K2013-010-01) on September 10, 2013 and Research Ethics Approval Committee for Health of University of Bath (REACH reference number: EP 14/15 58) on the 12th November.2014.

Chapter 4: Qualitative Research— Action Research

Action research has been employed in many healthcare settings in the UK since Kurt Lewin coined the phrase in 1947 (Lewin, 1946). Its particular strength lies in the coupling of participation and research to action, all of whom are involved in the change process. Action research is a period of inquiry that describes, interprets and explains social situations while executing a change intervention aimed at improvement and involvement (Hart, 1995). It is problem focused, context-specific and future-oriented process in which problem identification, planning, action and evaluation are interlinked. Theory may be generated and refined, and its general application explored through the cycles of the action research process. Specifically, the methodology has the potential to be useful in areas such as developing innovation, improving healthcare, developing knowledge and understanding in practitioners, and involvement in users and staff. In theory, action research is presented as a cycle of problem identification or situation analysis (including reflection), planning, action (implementation of change and monitoring) and evaluation, which may lead to identification of new problems, planning, action and evaluation, and so on. Action research provides a framework and overcome the separation of theory and research from practice. The movement between reflection, research, action and theory that may occur in each phase of action research has the potential to produce experientially and professionally relevant knowledge. These changes and developments are captured and evaluated through reflection and/or qualitative and quantitative research, thus potentially leading to concrete or substantive theories.

Action research is a cycle research model of four steps (Kemmis, 1988): plan, action, observation, reflective discussion. This study tried to analyse and solve the practical problem and develop a feasible creative expression therapy pathway for Chinese people with dementia through action research.

The purpose of this part was to develop a feasible creative expression therapy for Chinese people of dementia, which would be a practical guide for hospitals, community, long-term care institutes and homes. The action research was undertaken on 3 sessions for people with dementia from the geriatric wards, long term care institution and their homes respectively. 31 people affected by dementia took part in the 7 turns action research. In each turns, the research team participated together in the implementation, modification and improvement the programme following the process of plan-action-observe-rethinking cycle.

1 Sample

The data collection of action research may involve qualitative and quantitative methods so that the sampling strategy could always be purposive sampling (Field & Morse, 1985). In addition, the sample is determined by the depth and breadth, time and resources of the research. The typical case sampling is to choose the typical case, by which the researcher could explore the general situation of the research phenomenon (Chen, 2003).

2 Participants

This study applied typical case sampling (Wei et al.,2012) to acquire 31 cases of people with mild and moderate dementia from geriatric wards of a general hospital, a welfare home, and patients' homes in Fuzhou. With the help of the directors and doctors of the institutes, the participants eligible for the following criterion were screened. The research team explained the meaning and the purpose of the study to the staff of geriatric wards and invited the elder people with dementia to participate the activities with help of staffs. Finally, the eligible and voluntary patients' families or guardians read and signed the informed consent.

(1) Inclusion criteria:

①Age \geq 65;

②Dementia diagnosis conformed to WHO ICD - 10;

- ③Mini-Mental State Examination (Folstein et al., 1975) score of ≥ 11 but < 27 ;
- ④The ability to understand and speak mandarin or dialects of Fuzhou city, hearing adequate to hear the programme dialogue, eyesight adequate to view the programme stimulus picture.

(2) Exclusion criteria:

- ①With advanced terminal illness;
- ②Displaying behaviour that would make interview impossible, such as constant wandering, shouting, or aggression;
- ③Having a diagnosis of learning disability.

Among 31 cases in this study, their age 69-94, averaged 84.8 ± 6.4 . While 14 cases are men and 17 women, 13 cases were graded MMSE score 21-26 and the others 10-20.

3 Action research methods

3.1 Organizing research team

We organised research team including a leader, 2 clinical specialists, 4 facilitators of activities. Their responsibilities are as follows:

- (1) The tutor of the research (25 years of work experience, Master), the leader of the team, to design the research project, to train the team member, to participate the study, to organizing the reflection and discussion and to modify the action plan.
- (2) Clinical nursing specialists (14 and 32 years of work experience, Master and Undergraduates), to guide the activities, solve the practical problem during implementation, participated reflection and discussion.
- (3) Facilitators (3-13 years of work experience, Undergraduates), to implement and improve the project, observe and collect data, evaluate the outcome, participated reflection and discussion.

3.2 Designing the initial CE programme activity plan

CE programme (TimeSlips) was developed by Anne Davis Basting. The research team bought the TimeSlips operation right and acquired training online from Center on Age & community of Milwaukee of University of Wisconsin.

Taking into account literature review and clinical experiences, we designed the initial CE programme according to TimeSlips programme. We selected the pictures used in the activities. 10 experts, including geriatrician, neurologist, nursing specialists, validated and modified the activity plan through Delphi approach. Each session of action research has implemented the programme twice a week, 45 minutes a time for 6 weeks.

3.3 Data collection

We employed observation, semi-structure interview and tools to collect the data to explore the process and effect.

3.3.1 Observation data

Observation is a primary method to recognize the world and carry on research (Li & Pan, 2012). The research members were keeping keen oversight to collect data and document objectively, systematically and ethically.

(1) Constructed observation

The research made an observation plan and followed the observation outline or document form to acquire data (Li & Pan, 2012). During the intervention of CE programme, “CE Observation Form” (Appendix III) was used to assess attention and engagement of the participants. The observation form is recomposed from the “Group Observation Form” by Lai jinyu (Lai & Mo, 2002), covering 6 aspects : Be willing to participate, Attention, Ability to express, communication, level of involvement, level of enjoyment, mood, total speech number of times, total speech time. With the help of the observation, the participants’ change before, during and

after intervention were compared.

(2) Non-constructed observation (Li & Pan, 2012)

The researcher observes people and event in an open situation. In this study, through the note, video and camera, participants' attitude, engagement, interaction with others and mood, etc was observed and documented.

(3) Time-sampling

Before observation, researcher determined the observing dimension and form, and then selected some period of time to observe and record a certain behaviour or event (Ideological and Political Work Department of Ministry of Education of the People's Republic of China, 2010). It is one of observation method usually used to make sure whether some behaviours happen, the occurrence frequency and lasting time. Research team watched the engagement behaviour and mood of participants in the first week and 7th week pre- and post- intervention from Monday to Friday. Each participant was observed for 10 seconds and his (her) behaviour and mood was written down until every participant was observed for about 10 minutes. After having a 5-minute rest, we continued next turn of observation. The daily observation time lasted 6 hours. To keep the participants from having the feeling of nervousness caused by being observed, the observer stay in a corner not to be noticed. The behaviour of participants was recorded in terms of representing the following four behaviours, which was consulted from the researches by Proctor (Proctor et al., 1998) and Lawton (Lawton et al., 1996).

a. Disengaged. Participant is inactive, sitting passively or sleeping, or involved in unpurposeful activity such as fiddling with clothes, smoking or aimless walking.

b. Non-social engagement. Participant is engaged in purposeful activities which do not involve social interaction with others; for example, combing hair, reading, watching television, actively listening to music, knitting. If it becomes clear that the participant's engagement is not functional (e.g. they repeatedly vacuum or wipe the same place, wander aimlessly), then change code to disengaged or

challenging behaviour, whichever applies.

c. Social engagement. Participant is engaged in some form of communication with others where there is a state of reciprocity with at least one other person or the participant is initiating contact with another person. This includes recognizable speech, attempts to speak, vocalizations, signs or gestures, physical prompting in a manner which gains, attempts to gain or maintains the attention of another person. It also includes clearly giving attention (as evidenced by eye contact or orientation of the head) to another person who has begun to interact with the subject.

d. Challenging behaviour. Participant is engaged in solitary repetitive, non-functional motor activity (e.g. body rocking, pacing), verbal activity (e.g. crying out, grunting, continuous swearing), self injury, aggression to others, damage to property or other inappropriate behaviour such as spitting, pestering others or stripping.

We used Observed Emotion Rating Scale (Appendix VIII) to record participants' affect (Lawton, 1999).

a. Anger. Physical aggression; yelling; cursing; berating; shaking fist; drawing eyebrows together; clenching teeth; pursing lips; narrowing eyes; making distancing gesture.

b. Fear or anxiety. Shrieking; repetitive calling out; restlessness; wincing/grimacing; repeated or agitated movement; line between eyebrows; lines across forehead; hand wringing; tremor; leg jiggling; rapid breathing; eyes side; tight facial muscles.

c. General alertness. Participating in a task; maintaining eye contact; eyes following object or person; looking around room; responding by moving or saying something; turning body or moving toward person or object.

d. Pleasure. Laughing; singing; smiling; kissing; stroking or gently touching other; reaching out warmly to other; responding to music (only counts as pleasure if in combination with another sign).

e. Sadness. Crying; frowning; eyes drooping; moaning; sighing; head in hand;

eyes/head turned down and face expressionless (only counts as sadness if paired with another sign).

f. Other (neutral). Category was added for null behaviour that did not fit into the existing categories, such as sleeping and being fed.

3.3.2 Interview data

Interview (Chen, 2000) method is a kind of research conversation, from which the researcher acquire the primary data from the research participants. In the semi-structure interview, the researcher had a list of questions or fairly specific topic, however the interviewee had a much more margin in how to reply. The relatively unstructured nature of the semi-structure interview is to provide insights into how participants view the world. Werner & Schoepfle (Werner et al., 2008) believed the outcome of observation could not reflect culture and research based more exclusively on interviews is an alternative and verification for the collection of qualitative data. Thus, this study employed the semi-structure interviewing to people with dementia, nurses and students to explore their experience and feeling during the programme.

Data Collection: The researcher conducted semi-structure qualitative interviews during the final week of the TimeSlips intervention to elicit reflections on the programme from participants (Appendix IV). Before interviewing, the researchers should explain the purpose, meaning and spending time as well as get consent of recording during interviewing. To protect the privacy of interviewees, the code was used instead of interviewees' names. We used various techniques such as rhetorical question, question closely, repeat, respond, etc. to get comprehensive and accuracy view and attitude that the interviewee wanted to express. Timely and deeply inquiries were needed to clear some vague information. The whole process of interviewing was digitally recorded and the recorder was put at an unnoticeable place to avoid feeling of nervousness. Meanwhile, we took a note of nonverbal information, such as tone, intonation, expression, movement, etc. And then data transcribed by the researcher, with identifiers removed. All data were

pooled into a single document.

(1) The experience of people with dementia

The face to face interview were held immediately following the final 2 TimeSlips activities and was arranged at the activity room or quite place outside in an undisturbed period. According to circumstance, every people with dementia was interviewed once to triple and lasted on average 20 minutes each time. The main interview outline was open questions as following:

Interview questions (for people with dementia)

- a. How would you describe the storytelling experience you just had?
- b. What changes do you think you have had? Could you give an example?
- c. What did you most enjoy about it? Would you want to do it again?
- d. What suggestion do you have?

(2) The feedback of performers

Focus group, a group conversation centre on a specific topic, was employed to interview the activity executors (Krueger & Casey, 2000). This research employed focus group to get feedback of performers. The focus group discussion was arranged in the reflection meeting taking about 30-60 minutes. The topic prepared in advance as following:

- a. What differences have you noticed the participants in the TimeSlips sessions? What caused the changes?
- b. What have you learned from the TimeSlips programme (about the participants about yourself, about people with dementia in general)? Try to give examples.
- c. Could you please conclude the advantage and disadvantage of the programme and your suggestion?

3.3.3 The measuring tools

To compare the effect of CE on personal and social function, we used Mini-Mental State Examination (MMSE) (Zhang, Z.J., 2005) and Quality of Life-Alzheimer's

Disease (QOL-AD) to test participants face to face at the week0 and week7.

Mini-Mental State Examination (MMSE) is a brief, widely used test of cognitive function, with good reliability and validity. (Folstein et al., 1975)(Appendix V). This study used Chinese version by Zhang Mingyuan. It is an 11-item clinical assessment of global cognitive function. The test covers a variety of cognitive domains, such as orientation to time and place, short- and long-term memory, registration, recall, constructional ability, language, and the ability to understand and follow commands. The maximum score is 30. (Appendix V)

The QOL-AD , brief and self-report questionnaire has 13 items covering the domains of physical health, energy, mood, living situation, memory, family, marriage, friends, chores, fun, money, self and life as a whole. It has good internal consistency, validity and reliability (Logsdon et al., 1999). The tool was designed specifically to obtain a rating of the patient's Quality of Life from both the people with dementia and the caregiver. It was developed for people with dementia, based on people with dementia, caregiver, and expert input, to maximize construct validity, and to ensure that the measure focuses on quality of life domains thought to be important in cognitively impaired older adults. It uses simple and straightforward language and responses assessments of the individual's relationships with friends and family, and staff as well as physical condition and mood. The tool rated on a four point scale, with 1 being poor and 4 being excellent. Total scores range from 13 to 52. It generally takes caregivers about 5 minutes to complete the measure about their patients; for people with dementia, the interview takes about 10 to 15 minutes to administer. (Appendix VI)

3.4 Data analysis

The data was comprised of process and outcome of the treatment by means of qualitative and quantitative collection.

3.4.1 The analysis of qualitative data

The analysis of qualitative data is actually an induction thinking way although there are different qualitative research theories. The primary step should be carried out (Li & She, 2006):

- a. To be familiar with the data, listen repeatedly and record reflective notes.
- b. To transcript data, such as interviewing data and field notes.
- c. To reorganize the data and built index for abstraction and identification of the original data.
- d. To characterize some specific topic to protect privacy.
- e. To code the data
- f. To induce and interpret the themes and categories.
- g. To find the relevance between the themes or categories
- h. To generate a new theory or complement an old theory.
- i. To correlate and rectify the theme and categories.

3.4.2 Statistic analyses

Analyses were performed by SPSS on version 11.5. for Windows. Data were checked for accuracy and completeness, de-identified to protect privacy, and double entered to minimize data-entry errors. Descriptive statistics were computed to obtain a demographic profile. The descriptive analyses, Wilcoxon signed-rank test, T-test were used to evaluate the effect of the MMSE and QOL-AD. Observational data on participants' engagement were analysed by conducting independent chi-square tests. A .05 level of significance was used to evaluate differences.

3.5 Quality control

Before intervention, the experts have verified initial plan scientific and operable. All the facilitators were trained according to the standard activities pathway. In qualitative data collection, purposeful sampling is used, but rigorous sampling procedure will be also conducted. To prevent the participants dropping out, research team propagandized the research meaning and purpose actively and respected the right of consenting and privacy of participants during recruitment. In

addition, the research team held a no-blame and patient-centred attitude to the participants and have built a trust relationship a gracious way. During the observation, we conducted dual recording of information. To minimize reactivity of participants to being observed, observations were made from unobtrusive place. In data analyses, being kept a neutral attitude and let other team member examine and verify the research process and outcome.

4 The process of the action research

We have carried out 3 successively sessions of action research in elderly wards, nursing homes, private homes.

4.1 The first session—action research on people with dementia in geriatric ward

4.1.1 Plan (session 1)

The initial action plan was composed of 3 parts:

- (1)The first part: Assessment before activity, including baseline of participants and suitable time;
- (2)The second part: Preparation before activity, the space, paper, and pens, etc.
- (3)The third part is the activity main process:
 - a. the prelude step: self-introduction, welcome the storytellers to the activity, read a story from the previous session;
 - b. the main step, select a new image, ask open-ended questions, write down all responses, retell the story (every 5 answers or so).
 - c. the ending step: build to a final retelling and title the story, thank the storytellers and say goodbye.

NB: The images should: promote the stories and imagination easily; not be complex and divergent; be clear, either black and white or color; be easily seen that the size of paper is big enough.

Ashton (Ashton, 1993) and Osborn (Osborn, 1989) suggested that the feasible

frequency of group activities is once or twice weekly. Considering the daily routine of people with dementia and the fixed schedule of the wards, we arranged twice weekly, 6-week totally 12 times TimeSlips activities. Each activity begun at 3:30 pm and lasting 45 minutes.

4.1.2 Action (session 1)

(1) Screening the participants:

The participants who were willing to be contact were screened according to the inclusion and exclusion criteria. The sample initially consisted of 12 participants, however, a people with dementia dropped out at early stage because of activity time conflicted with rehabilitation treatment, and another people with dementia quit at middle stages as the bad state of illness. Finally, 10 cases of people with dementia finished this session of action research. We collected age, gender, education, marital status, occupation before retirement and self-care from residents' charts and their care giver.(Table 4-1)

Table 4-1. The Basic Situation of the Objects in Geriatric Ward							
No	Gender	Age	Marriage	Education	Profession Pre-retirement	Self-care	MMSE Scores
A01	Female	88	Married	Primary School	Officer	Fully Self-cared	23
A02	Male	83	Married	Secondary School	Officer	Partially Self-cared	20
A03	Female	93	Widowed	Secondary School	Officer	Partially Self-cared	25
A04	Male	94	Widowed	University	Officer	Partially Self-cared	20
A05	Male	92	Married	Private School	Officer	Partially Self-cared	20
A06	Male	88	Married	Primary School	Soldier	Partially Self-cared	18
A07	Female	84	Widowed	Secondary School	Doctor	Fully Self-cared	22
A08	Female	88	Widowed	Primary School	Officer	Fully Self-cared	26
A09	Male	86	Widowed	University	Teacher	Partially Self-cared	18
A10	Male	94	Widowed	University	Officer	Partially Self-cared	20

(2) Recruiting volunteer

The team pasted poster and organized meeting to publicize the meaning of the research. The responsibility of volunteer was: taking part in the implementation of the programme, assisting communication, going to toilet and other demanding of people with dementia, giving assistance of observation and data collection, participating reflection and discussion. 10 interested intern students volunteered to participate in the programme. They read and signed the consent form and were admitted that whether they participating the programme was irrelevant to their accomplishment evaluation. 3 theoretical lectures and 1 video class were conducted by TS-certified trainers.

(3) Implementing TimeSlips

The plan was implemented twice a week for 6 weeks on the basis of the protocol

of “CE storytelling treatment for people with dementia ” which was revised during the action. Three rounds action research circle were undertaken in this session.

a. Assessing the baseline of the people with dementia:

To collect the baseline condition before intervention, researchers consulted from the charts, communicated with people with dementia, families, care givers and primary nurses. The data were diagnosis, disease condition, communicating ability, level of audition and vision, MMSE and QOL-AD score.

b. Preparing for the activity

The facilitators and assistants arrived at the activity place in advance for preparation. ①To ensure the space relatively quiet and without distractions. It is better to put the chairs in a semi-circle, leaving space between them in case the facilitator needed to move right next to someone in order to be heard. ② Prepare the supplies of activities such as images, name tags, white board or paper big enough to be seen, markers. ③ Conductors were ready for their responsibilities. They were facilitator, recorder, and research assistants to help meeting communicating, toilet and other demands of people with dementia for operability and safety.

c. Encouraging creative expression

The facilitator applied “open-ended” question to encourage imagination and individual expression. The questions could be 5W1H , (When, Where, Who, What, Why and How).Implementers tried to write down all responses to let the storyteller know they had been heard, and then retell the story purposefully to refocus the storytellers. When the energy fades and people feel a little tired of the story, the facilitator weaved to a final retelling story and gave special recognition to storytellers who said outstanding things.

d. As soon as the activity ended, we sent them back to their rooms and put things

of activity room in order.

4.1.3 Observation (session 1)

During implementing process, we collected data through on-site observation, questionnaire, interview and recording the video and audio.

(1) Observation data

In different stage of all the 12 times implementations, the people with dementia have different feature. Overall, with the intervention promoting, the elderly people have been making a progress gradually as follow.

a. In preliminary intervention

The old men might feel anxious and uneasy. Although some people with dementia admitted in same ward, they seemed never to communicate and know each other. They were unfamiliar to the activity as well as. Thus better communication could ease their feeling of tension. Implementers tried to be calm with people affected by dementia to build a friendly communicating environment. To speake slowly and in short, clear sentences as well as to reinforce message with a gesture, etc. After a few times activities, the old men could understand the activity process and increase their engagement.

In second time TimeSlips : During the activity, some old men presented unconcerned face, some just stared at the image in the hand and ignored the surrounding, some seemed unwillingly to enjoy the activity and gazed around purposelessness, most old men just sat quietly and have no interaction with other participants.

b. Intermediate stage of intervention

The elders were more tacit to the activity model. As the creative ability was stimulated, they showed more active engagement. They knew and were familiar more with each other and have a joy share in the storytelling. Besides, the relaxed and joyful atmosphere would be helpful for a better activity experience. In this stage, the facilitator could indicate and adjust the topic according to their personal

characteristic. Meanwhile, listening attentively and positive feedback were always needed for stirring up enthusiasm continually.

In the 6th time activity: elders echoed to the facilitator much more actively and attentively gradually. Specially, the elder of sample A02 had made a great progress that he combined two times images to develop an interesting story.

c. In the later stage

TimeSlips has been up to a mature stage throughout 12 times activities, from which the effect have been revealed. The willing of attendance and engagement elevated, interaction between participants increased, ability of communicating and attention promoted, nevertheless, depressed mood decreased, thus, the quality of life improved.

Note in the 10th activity:

Today, five elders arrived at the activity room in advanced. They say hello to each other and us and then chatted and laughed freely in a harmonious air.

Note in the 11th activity:

Today, the old man of sample A04 sang an old song for participants complied with their clapping hands in rhymed beats. The exciting mood reached to a highest tide at that time.

(2) Interview data: the experience of people with dementia

The people with dementia (code :A01-A10) have been semi-structure interviewed for the experience of the activities. The interview data was analyzed and drewed 5 themes:

a. The programme was helpful so that they enjoyed.

Many participants believed that the programme was beneficial as they felt happy

and their life would not be boring.

A01: I feel fresh with energy and happy after the activity. The activity is wonderful and I am glad for your coming. Continue please!

A07: Hopefully TimeSlips launches here forever .

b. They enjoyed the story and creativity was inspired.

The open-ended question could invite the participants thinking and imagination. TimeSlips facilitators tried to invite, echo, and weave together all creative responses into the story. There were no “wrong” answers.

A04: We have respective thinking and talking in the storytelling . That is OK.

A06: I believe I am a good storyteller. To tell the story clearly is fine, isn't it? My story is getting better and better so I am interested in it. Speaking out is good, while no speaking is bad.

c . Enhance the social relationship and interaction

With the help of TimeSlips, the elders had been getting to know each other and extended this kind of relationship to their daily life, contacting, chatting, concerning, etc.

A08: It is boring in the ward,... ..., the activity can make us communicate.

A03: It is fine to have such a good chance; we could be familiar and communicate with one another.

d. Improving ability of communicating, ameliorating negative mood

In the interviews the elders reflected that the activity made their communicating ability increase and expression be well organized. They were willing to communicate with others and turning into a better mood.

A10: Storytelling could take exercise of eloquence because my speaking don't get stuck any more. In short, the benefit is great!

A02: Certainly nice! Taking part in the activities has got a good spirit. The more we touch, the more story rich.

A07: Being there (the activity room), my feeling is getting better and head rolling quicker.

e. Recognising self-esteem and feeling achievement

A04: it is absolutely happy that I have chance to speak out and express my opinion. That means you have existence value. Otherwise, nobody take notice of you. Overall, I am satisfied to convey my full viewpoint freely. I talk, I happy!

(3) Interview data: feedback from the volunteer students after participating in the programme

Focus group interview of volunteer students was held (code: S01-S14)) and drew three themes:

a. The elders admitted lack of company in hospital: Many students described the life of people with dementia in hospital with the words: boring, lonely, lack of company, etc.

S03: The elders live a boring life as they had to face same environment and things everyday. Longtime living in hospital, narrow activity space, lessened social contact is liable to change their attitude and cause negative mood rising.

S12: They lack of love, company, chance of communicating. This make them be solitary. Thanks to activities they could get to know one another and involve in communicating, thus the feeling of lonely lower and quality of life improved.

S07: The elderly always fear loneliness. For the activities gather them joyfully, they may have a happy old age.

b. Participating in the programme was benefit for improving the elders quality of life.

① The stirred up creativity is surprising. After the programme, most students found that the stories told by the people with dementia were totally unexpected and their creativity is amazing.

So4: The grandpas talked about many things we could never image...We benefit a lot as well as.

So8: The programme let us see another side of people with dementia, such as their wide knowledge and rich past experiences.

② The wider interpersonal communication and increased social contacting.

So9: A doctor told me :”Mr... always say nothing before, surprisingly, he could say hello to me after your programme. So great change! ”That is the most impressive thing and I have a sense of achievement.

③ Enjoying the stories and promoting positive mood. During the programme, the elders were brought into fully play and talked freely. Besides, they were more self confident and feel more pleased as they got encouragement and applause.

So1 From the first time activities to this day, we witness their whole process of changes which brought unlimited pleasure to the elders.

c. Participation in activities helps improve their ability.

① Building the empathy. The research members could look at the world through the windows of the people with dementia. They used transpositional consideration to the thinking and demand of the elders.

So6: We met dementia in the books before. We truly touched the dementia elders through this programme which is meaningful for us to learn them.

② Enhancing the ability of communicating.

These communicating skill and precious experience would forest the students a humanistic sense in their future professional career.

S10:We have few chance to close the dementia elders before, due to the programme we learned how to interacted with them effectively. Very rare opportunity !

③ Foresting a positive attitude

Involving in the storytelling activities with people with dementia, the students held more positive attitude toward the people with dementia. Meanwhile, in the programme the students may clear up some misunderstanding and master the skill of communicating with people with dementia which is benefit for their professional development.

S05: It is the disease that caused their behaviour inconvenient rather than themselves. Never ignore their suffering, instead, care more and do more for them.

S11: We dislike elders as they chatter endlessly and have difficult to communicate.

By means of this programme, I feel they are a group of lonely people, they need care.

Only if you treat them truly, they treat you faithfully.

(4) Effect assessment

a. The CE storytelling observation form

With the help of CE storytelling form, we evaluate the effectiveness of the 12-time TimeSlips activities for people with dementia. We represent the first time, 6th time, 12th time as preliminary, intermediate and last intervention stages. The comparison undertook between preliminary and intermediate stage, intermediate and last stage, preliminary and last stage as follow. (Table 4-2, 4-3, 4-4)

Table 4-2. Comparison of the Effects between Early Intervention and Mid-term Intervention (N=10)								
Items	Negative Ranks ^a			Positive Ranks ^b			Z ^c	P
	Number	Mean Rank	Sum of Ranks	Number	Mean Rank	Sum of Ranks		
Be Willing to Participate	0	—	—	0	—	—	—	—
Attention	2	3.50	7.00	5	4.20	21.00	-1.265	0.206
Ability to Express	1	4.00	4.00	7	4.57	32.00	-2.111	0.035*
Communication	2	1.50	3.00	1	3.00	3.00	0	—
Level of Involvement	2	3.00	6.00	3	3.00	9.00	-0.447	0.655
Level of Enjoyment	1	2.00	2.00	2	4.00	8.00	-0.577	0.564

Notes: ^amid-term intervention<early intervention. ^bmid-term intervention>early intervention. ^cWilcoxon Signed Ranks Test Statistics. . *P<0.05

Table 4-3. Comparison of the Effects between Mid-term Intervention and Later Intervention (N=10)								
Items	Negative Ranks ^a			Positive Ranks ^b			Z	P
	Number	Mean Rank	Sum of Ranks	Number	Mean Rank	Sum of Ranks		
Be Willing to Participate	0	0	0	3	2.00	6.00	-1.732	0.083
Attention	0	0	0	7	4.00	28.00	-2.460	0.014*
Ability to Express	1	2.50	2.50	3	2.50	7.50	-1.000	0.317
Communication	0	0	0	6	3.50	21.00	-2.251	0.024*
Level of Involvement	1	4.00	4.00	7	4.57	32.00	-2.111	0.035*
Level of Enjoyment	0	0	0	4	2.50	10.00	-1.857	0.063

Notes: ^alate intervention<mid-term intervention". ^blate intervention>mid-term intervention". . *P<0.05

Table 4-4. Comparison of the Effects between Early Intervention and Later Intervention (N=10)								
Items	Negative Ranks ^a			Positive Ranks ^b			Z	P
	Number	Mean Rank	Sum of Ranks	Number	Mean Rank	Sum of Ranks		
Be Willing to Participate	0	0	0	3	2.00	600	-1.732	0.083
Attention	0	0	0	8	4.50	36.00	-2.598	0.009**
Ability to Express	1	3.00	3.00	7	4.71	33.00	-2.165	0.030*
Communication	0	0	0	5	3.00	15.00	-2.121	0.034*
Level of Involvement	0	0	0	3	2.00	600	-1.732	0.083
Level of Enjoyment	0	0	0	8	4.50	36.00	-2.598	0.009**

Notes: ^alate intervention<early intervention. ^blate intervention>early intervention ". **P<0.01, *P<0.05

The tables revealed that there were significantly different in expression ability between preliminary and intermediate stage. Other indicators have no significant difference. However, the positive rank sum take an advantage show that people with dementia indicators still have an improved tendency. The table4-3 indicated a significant difference of attention, interaction, engagement between intermediate and last stage. This result was in keeping with the observation outcome. In terms of attendance willing, may be due to the memory deterioration of the participants which let the staff remind them before the activities every time. However, the interview data showed they like the programme very much.

b. CE storytelling daily observation form

Within 6-week TimeSlips intervention, 4 trained observer employed time-sampling method have observed the people with dementia pre- and post-intervention, that is in week 0 and week 7, from Monday to Friday, 10 days 240 pieces daily observation totally. The changes of engagement and mood were compared (Table 4-5)

Table 4-5. Comparison the Engagement and Emotion of People with Dementia before and after the Intervention

Items	Before the Intervention ^a		After the Intervention ^b		χ^2	P
	n	%	n	%		
Engagement						
Disengaged	361	31.26	319	27.08	4.924	0.026*
Non-social Engagement	605	52.38	582	49.41	2.066	0.151
Social Engagement	189	16.36	277	23.51	18.656	0.000**
Challenging Behaviour	0	-	0	-	-	-
Emotion						
Pleasure	29	2.51	36	3.06	0.640	0.424
Anger	1	0.09	1	0.08		1.000 ^c
Anxiety/ Fear	0	0	1	0.08		1.000 ^c
Sadness	0	-	0	-	-	-
General Alertness	781	67.62	864	73.34	9.195	0.002**
Other (Neutral)	344	29.78	276	23.43	12.067	0.001**

Notes: ^a The total number of incidents of the objects' engagement and emotion is 1155 before the intervention. ^b The total number of incidents of the objects' engagement and emotion is 1178 after the intervention. ^c Fisher probabilities.
**P<0.01, *P<0.05.

As the table 4-5 given, with regard to engagement behaviour, proportion of social engagement behaviour were higher while lower proportion of disengaged after the programme. In aspect of mood, they showed higher percentage of alert nevertheless lower neutral.

4.1.4 Reflection and modification (session 1)

Every two weeks we rethought and discussed the problems emerged in the intervention. We consulted the people with dementia feedback and seek improved method to solve the problems so as to modify the protocol of CE storytelling treatment for people with dementia. Three rounds circle was finished at this phase.

The first round action research reflection:

- 1) As most participants in this study were advanced age with vision and hearing loss more or less, they needed to wear glasses and hearing-aids to ensure the activity effect.
- 2) Memory deterioration may lead to missing the time of activity.
- 3) Because of the limitation of the time, the self introduction was very simple so that the elders still felt unfamiliar with each other after two times activities.
- 4) For two weeks intervention, the elders turned from strangeness to familiarity, from disacquaintance to interaction, consequently engaged the programme more actively.

The revised protocol (the first round):

- 1) Each time before the intervention, the team members invited the participants initially and reminded them to bring glasses and hear-aids.
- 2) Using microphone to make elders hear clearly. Meanwhile, sitting beside them to convey the information repeatedly and timely and avoid ignoring anyone.
- 3) Reminding the elders next time of activity at ending phase.
- 4) Adding a special self introduction activity temporarily, including name, bed number, hobby, etc. Adequately introducing within the people with dementia and facilitators in the first time activity would helpful for the subsequent activities.

The second round action research reflection

- 1) The adaptability of some care givers was unsatisfactory as they complained that the programme upset the route of daily care.
- 2) For 4 weeks intervention, the elders enjoyed the process of the programme and were stimulated creative thinking mutually. In addition, we find some elders with open personality acquired more attention and applaud due to speaking actively, on the contrary, some were keeping silent most time.

The revised protocol (second round):

- 1) Explaining the meaning of the programme to the caregivers, besides, before the activity, talking the time schedule over with care givers so that not conflicting with other treatment and care.
- 2) At the prelude of activity, the facilitators introduced the purpose and meaning of the programme again to deepen their understanding.
- 3) The facilitators should equally keep a watchful eye on every participant rather than only some outstanding performance.
- 4) Use the power of focus to invite other people to participate as well. Usually, earnest encouragement and praise were needed throughout the activity. Furthermore, the facilitators could prepare 2-3 images for those inactive participants to choose.
- 5) At the beginning, some calm and leisurely old songs may promote emotional communications.

The third round action research reflection

- 1) The facilitators should be equipped with knowledge of geriatric psychology and pedagogy because of the diversity of the demographic variables.
- 2) Adding some matters needing attention in the protocol for more successful following activity.
- 3) For 6- week intervention, we recognised the effect on the people with dementia in the hospital. However, whether the hospital staffs could act as the facilitators? Whether the programme could implement in Chinese long term care system? Further studies were needed.

The revised protocol (third round)

Adding some detail attention to improve the protocol

4.2 The second session: action research in a LTC setting

4.2.1 Planning (session 2)

We organized research team again for the action research to improve the protocol of CE storytelling treatment in Fuzhou First Social Welfare Home.

With the support from the director of the institution, the place was arranged in the activity center with well equipped audio system, sufficient light. The room was spacious enough to put the chairs in a semi-circle, and relatively quiet and without distractions. The elevator and toilet was available and nearby for conveniently arrival and toilet demanding.

Considering the dementia elders daily schedule and the original activity scheme of the nursing home, the 45-minute 6-week 12 times TS activities was arranged at 3:30pm on Thursday and 10:00am on Friday.

4.2.2 Implementation (session 2)

(1) Screening participants in LTC setting

We recruited participants abiding by the inclusive and exclusive criterion. 12 elders were selected initially but an elder dropped at preliminary stage as a worse disease condition and admitted to the hospital. At this session, 11 participants finished the action research finally (B01-B11). Their geographic data as following. (Table 4-6)

Table 4-6. The Basic Situation of the Objects in the Second Phase of the Study							
No	Gender	Age	Marriage	Education	Profession Pre-retirement	Self-care	MMSE Scores
B01	Female	80	Widowed	University	Teacher	Fully Self-cared	21
B02	Female	88	Widowed	Secondary School	Teacher	Partially Self-cared	21
B03	Female	83	Widowed	Secondary School	Nurse	Partially Self-cared	26
B04	Female	69	Widowed	Illiteracy	Farmer	Partially Self-cared	10
B05	Male	87	Widowed	Secondary School	Officer	Fully Self-cared	24
B06	Female	75	Widowed	Primary School	Worker	Fully Self-cared	21
B07	Female	88	Widowed	Secondary School	Officer	Fully Self-cared	12
B08	Male	88	Widowed	Illiteracy	Farmer	Partially Self-cared	12
B09	Female	90	Widowed	Primary School	Worker	Partially Self-cared	17
B10	Female	79	Widowed	Secondary School	Officer	Partially Self-cared	18
B11	Female	90	Widowed	Primary School	Farmer	Partially Self-cared	18

(2) Organized research team

Except for the original leader, 2 clinical specialist nurses and 4 facilitators, we recruited 3 nurses, who aged 25-29 and 2-5 years work experience from the hospital, instead of those students in the first stage. The new members were trained as well.

(3) Implementing of TS

The research team carried out the intervention twice a week and 6 weeks on the basis of the revised protocol in the session1. Meanwhile, the programme was kept on being reflected and modified in 2 rounds circle of action research.

4.2.3 Observation (session 2)

The content and method of observation was same as session1 action

research.

(1) Observation data from elders in LTC setting

At the beginning, the dementia elders in nursing home were not able to speak out because of shyness. However, with the active facilitation and encouragement, the elders understood and trusted one another so as to eliminate the tense and defensive feeling. They discussed together and yielded the greatest creativity in the harmonious atmosphere accompanying with an increased interaction and decreased negative mood.

Bo8: At beginning , he was taciturn, felt uncomfortable with others, and only a few overcautious words as to be asked. However, as time went on, he would say hello with others before the activity. Moreover, he could express an integrated story and sometimes developed a topic on his own initiative. He enjoyed the programme.

B11: She is a cheerful and active woman. She had been more initiative and willing to interact and enjoy with others since beginning. After some times, except for tacit understanding and participating in the activity, she could use her imagination and develop a story according to her past experience so as to be welcomed. Even more active, she always helped other participants press the button of the elevator and backed to their rooms together.

(2) The interview data: experience of the people with dementia in LTC setting

a. Agree with the benefit of the programme.

Most elders believed that the activities is benefit for themselves and improved their life quality. Many feedback as: "Certainly I feel more happy !"; " it (the programme)can develop mind. We communicate and know more." ; " it is great to know new things.", " play together is wonderful! Time is flying!" ; "we say hello to each other";" We are getting to knew one other "

Bo3: Once a time , I fell down and blacked (smudged) my hands , many people ask me: “ how about your hands? They are black!” I told them : “ I fell down.”

They care for me and inquired whether I can move.

B05: The activities let us have something done, otherwise, we shut ourselves in door, that is boring. I am pleasure to joy the programme. In addition, the programme enhanced the relationship and social interaction.

b. Their physical and psychological status might influence the participating. During intervention, the willing of attention, attention and engagement could be affected by being poor rest, unwell, in bad mood, etc. It is important that the implementers should give elders more concern and encouragement at that time.

B02: The performance deepened on by brain. If my brain is clear, I could complete anything, otherwise, I could do nothing.

B09: Only I feel good, would I go to the activity.

(3) Interview data: the feedback of research members

Focus group (code N01-07) interview was held and drew out 3 themes affected the people with dementia involvement .

a. Attitude of the implementers and quality of facilitating. The positive attitude would affect the engagement.

N01: I believe that the attitude is one of an essential element contributing to active involvement.

N06: The grandmamma told me: you are so kind and warm hearted that you call us grand pa and grand mama. You show respectful manner to us . We need it!

By means of appraising, concerning and motivating the elders, the activities made them express themselves freely and feel happiness from self-esteem.

No04 it is due to be more care , that have they higher activities .

Only the facilitators tried to concentrate the participants' attention, could the participant stir up their creativity.

No07: Now the elders are in a better spirit state, longer concentrating time , therefore more vigorously communicating.

In the focus interview, the interviewees agreed consistently that the high quality of facilitation would be benefit for an active mind and development of imagination. Pleasure air, safe environment, respecting individual difference, clear expression, incisive method and opening facilitating, etc. were needed all the way. Those should be trained, modified and improved throughout the intervention.

b. The interaction between the participants. At first, the elders were passive , however , they turned to be affected and enlightened by others lastly. So the implementers incited the interaction with the help of the people with dementia themselves and got a satisfy effect.

No13. Now they were interactive.....single point and single point respectively, sometimes inspired a wonderful story.

c. Physical condition and old experience: illness and depression were usually excuses for absence.

No05: Surely, if they felt not comfortable, they would not come.

When enjoyed the stories, the past experience and education influenced their engagement.

No3, I believe the stories must relate to their life experience. If I have not had that experience, I would have not any idea. I guess they couldn't tell something they never see.

(4) Effect evaluation (session 2)

The "CE storytelling observation form" was applied to evaluate the outcome of the programme for people with dementia in LTC setting. We compared their behaviour in first and 12th times, which represented as preliminary and later stage. (Table 4-7)

Table 4-7. Comparison of the Effects between Early Intervention and Later Intervention (N=11)

Items	Negative Ranks ^a			Positive Ranks ^b			Z	P
	Number	Mean Rank	Sum of Ranks	Number	Mean Rank	Sum of Ranks		
Be Willing to Participate	0	0	0	2	1.50	3.00	-1.414	0.157
Attention	0	0	0	10	5.50	55.00	-2.889	0.004**
Ability to Express	0	0	0	5	3.00	15.00	-2.236	0.025*
Communication	0	0	0	9	5.00	45.00	-2.739	0.006**
Level of Involvement	0	0	0	5	3.00	15.00	-2.236	0.025*
Level of Enjoyment	0	0	0	8	4.50	36.00	-2.640	0.008**

Notes: ^alater intervention<early intervention. ^blater intervention>early intervention. **P<0.01, *P<0.05

The table told us there was difference in the attention, expression, interaction, engagement and enjoyment pre- and after the intervention, consisted with the first phase outcome. The effectiveness was verified again in this phase.

4.2.4 Reflection and modification (session 2)

In this 6 weekly phase, we finished 2 turns action research round to continually improve the programme.

The forth round action research reflection:

1) We learned from experience of last phase that we have had a well introducing between participants and facilitators in the first time except for meaning and process of the programme. The elders came from different floor,

had never knew each other before. However, the brief introduction vigorously stirred the activity air.

- 2) The communication barriers, As some elders only understand Fuzhou dialect, the facilitators had to use mandarin and Fuzhou dialect alternatively. That easily made semantic interpretation became difficult.
- 3) The method of information conveying, because of difference existing in culture and expression ability, understandability, feasible speed, body language should be attached to communication.
- 4) Physical reasons, such as sleep insufficiency and uncomfortable feeling, might low down the enthusiasm to partake.
- 5) We found a few capable participants dominate the storytelling.

The revised protocol (4th round):

- 1) The facilitators should slow down their speaking speed, Fuzhou dialect firstly and mandarin again, so that the elders could understand clearly and feel considered.
- 2) To lay importance on the assessment of disease condition, communicating ability, educational level, characteristic of personality, interest of each participant before the programme, as well as physical and mental state before and in the course of every activity.
- 3) When a person dominates, this means that the process was really working well for the activity. But it was a group process, and you needed to be careful to invite others to participate as well. To animate the activity, asked the active or capable elders to assist passive ones.

Reflection of The fifth round action research

- 1) The elders in the nursing home have a high willing to participant the programme so that some of them arrived at the place in advance every time.
- 2) After a few times intervention, they involved the group initiatively and we could feel their anticipation and fondness for the programme and unwilling to part in the end.
- 3) From this phase, we believed that the TS was feasible to people with dementia in nursing homes as well as. The training manual told us one -to -one intervention were appropriate as well. Thus, what would happen if the

intervention carried on Chinese people with dementia living in their home ?

The revised protocol (5th round)

- 1) To chat and concern daily life with the participants who got the place earlier might gain more trust from the participants.
- 2) In later stage, let the elders know the ending time so that they could have a mental preparation. At the last intervention, we sent handmade postcards, photos, and gifts to participants and say goodbye.

4.3 The third session: action research on people with dementia living in home

4.3.1 Planning (session 3)

On the basis of last round action research, we made a strategy plan to implement TS intervention indoor for the people with dementia in their homes to further explore the CE implementation. With the help of neurological doctors of Fujian Provincial Hospital, we recruited eligible dementia outpatients. The programme was still twice weekly 6-week and each time was appointed prior with their family.

4.3.2 Action (session 3)

In accordance with the eligible criterion we recruit 10 participants as following (C01-C10). (Table 4-8)

Table 4-8. The Basic Situation of the Objects in the Third Phase of the Study							
No	Gender	Age	Marriage	Education	Profession Pre-retirement	Self-care	MMSE Scores
C01	Male	74	Married	Secondary School	Art	Partially Self-cared	24
C02	Male	84	Married	Secondary School	Officer	Totally Incapacitated	11
C03	Female	90	Widowed	Primary School	Farmer	Totally Incapacitated	10
C04	Male	82	Married	College	Officer	Fully Self-cared	20
C05	Male	85	Married	College	Officer	Totally Incapacitated	26
C06	Female	70	Widowed	University	Officer	Totally Incapacitated	16
C07	Male	88	Widowed	Secondary School	Officer	Partially Self-cared	19
C08	Female	80	Married	Secondary School	Officer	Fully Self-cared	18
C09	Female	83	Married	Secondary School	Officer	Fully Self-cared	25
C10	Male	86	Married	Secondary School	Officer	Fully Self-cared	26

Before the household interview, the members have learned the technique of indoor research, including appearance and dressing code, communicating art, method of getting trust, how to end activities , etc (Ma et al., 2005) (Shen & Xia, 2013). Then four facilitators have implemented 12 times household intervention to the 10 cases of people with dementia according to the revised Ts protocol, meanwhile, 2 rounds action research have been finished.

4.3.3 Observation (session 3)

The content and process were same as phase 1.

(1) Interview data, the experience of caregivers of home living people with dementia

We used convenient sampling and have had semi-structure interviews to 4 care givers. 3 themes were drawn from the interview, which was: novel and operable programme; involved and enjoyed together; improving understanding

and connection.

a. The novel and operable programme: the CE storytelling stimulated the creativity of the people with dementia and focused on what the person can do, rather than the abilities that have been lost owing to the disease.

"That is great! Look forward to your next coming."

"Grandmama is very happy! It is benefit that her brain get practice!"

b. The creative storytelling developed chances for people with dementia and their caregivers of expression selves, enjoying pleasure and developing together. Taking an example, a participant's wife took part in the activities with her husband every time. They were inspired, replenished and enjoyed mutually. She said: *"I can feel his progress that he speaks to me in full sentences. It is interesting to tell a story together."*

c. Creative engagement could help care partners open relationships and more deeply understand each other. Besides, individual stories might be more in-depth and pursue a storyline more fully.

(2) Interview data, the implementer's experience from the intervention on people with dementia living in their homes

The facilitators concluded that all the participants had made progress and the programme is worth to be popularized.

Before the activity, he (participant) was under the weather, nevertheless, I feel he is getting better after a few times activities.

In addition, some facilitator found the caregivers lacked of relevant knowledge of dementia care and its source.

"They often inquire me some question such as daily care, medication care, and option of auxiliary instrument etc."

"Each time I come, she told me about eating and sleeping of her husband and ask me something she thought abnormal."

Some facilitators suggest that social support are necessary, for example , daily care center, perfecting community service system, to relieve the burden of care givers and then improve care quality .Besides, the research team stressed the necessity of continue intervention to the people with dementia so as to solidify the effectiveness.

4.3.4 Reflection and modification (session 3)

This session has finished 2 rounds action research.

The 6th round reflection:

- 1) At beginning of the indoor visit, the participants and their families might feel strange to facilitators and more hesitant are being identified as the author, thus they presented sparingly.
- 2) Sometimes the elders refused to take part in the activities when they felt uncomfortable.

The revised protocol (6th round):

- 1) To know well and rationally use the skill of communication. Each time before indoor visit, connecting with families and making an appointment at an appropriate period.
- 2) To give sincere compliment for the people with dementia and their families so as to close the distance to them.
- 3) Try to explain the relevant knowledge of the disease patiently and get their understanding and cooperation.
- 4) If the elders in a low mood, we tried to transfer their attention or postpone the visit time till they feel better. Don't compel the people with dementia to finish the intervention task. We could observe and ask the reason of their contradicting and deal with it timely.

The 7th round reflection:

- 1) As the intervention went on, the people with dementia turned to anticipating the activity time and built a trust relationship with the facilitators. The people with dementia and their careers developed more interaction and enjoyed the

happy time and chance of development together.

2) Most families welcomed our visiting, however, a few were unwilling.

3) We find the families cared about the correctness of the storytelling rather than their creativity.

The revised protocol (7th round)

1) To analyse the uncooperative cause through careful observation and attentive inquiry. Meanwhile, to give explanation for the questions from families so as to ally their fear.

2) To lecture the families general knowledge of dementia and nursing techniques. 3) Firstly, to encouraging families taking part in the activities and let them know everyone have creativity without exception for people with dementia. Moreover, the people with dementia still keep the capability of development, learning and sharing. That is why we inspire the people with dementia to express themselves and there are no “wrong” answers. Lastly, the families should believe the elders still have unlimited possibility to develop and release potential abilities except rich past experience.

5 Outcome of action research

5.1 We developed “Creative storytelling for Chinese people with dementia” protocol through 3-phase and 7-round action research (Appendix IX)

5.2 Comparison of MMSE and QOL-AD pre- and post- intervention

The qualitative research carried on 3-phase,6-week and 12 times activities for 31 cases of people with mild and moderate dementia. The effectiveness was verified by means of MMSE and QOL-AD besides the observation and interview data. (Table 4-9)

Table 4-9. Comparison of the People with Dementia MMSE and QOL-AD Scores before and after the Intervention ($\bar{x} \pm s$, N=31)				
Items	Before Intervention	After Intervention	t	P
MMSE Scores	19.58±4.80	20.32±5.26	-1.696	0.100
QOL-AD Scores	29.03±5.54	31.90±6.93	-2.442	0.021

5.3 The display of some stories

Figure 4-1



Story 1

This is a story about Big White and Little White. They are father and son. Little White is a naughty boy and he always picked fights and usually won. This day, Little White is seized by Big White. Big White wants to bring his son back home and stop him making trouble outside. Little White is unwilling to home and look at his guys who are still playing. Little White waves his hands toward his friends and say: “Hi, guys, bye-bye! My dad arrests me and I can not play with you today.

Story 2

The two penguins are friendly, like man and wife, friends, Chinese People. They are play together. At this time, one looks toward left but another toward right. Probably they have a row. But later, they have made it up.

Story 3

Their names are polar birds. In the world of ice and snow, they are still friendly. There is love among animals even in the coldest environment. They are man and wife, hand by hand in love. Human beings should love each other and help each other either.

Story 4

Under blue sky and white cloud, although one bird looks toward left and the other toward right, they have same purpose, that is fighting to the bad weather together.

Figure 4-2



Story 1

In a village, this is a good harvest year. The man is making a big feast for a happy thing. All the vegetables are home-grown. This big meal manifests that national agricultural harvest is great so life in the countryside become better and richer.

Story 2

This story happed in a village, this family are making a wedding feast. A old chef is preparing the meal for guests. All the dishes are particular dealt with.

Story 3

This story is in a village. With the development of our country, the village is gradually prosperous and become a tourist spot, where attract a lot of visitors. A man has a business brain. Every day he cooks various foods and sells to the tourists. Not only to meet the needs of consumption but also to make some money. Particularly, they are pollution-free food, like home-grow vegetables and domestic chicken and ducks. Look, at his house, it becomes a clay-house from a thatched cottage.

Figure 4-3



Story 1

Two polar bears are walking in ice and snow. Mather walks in front of her baby. The baby runs after her mother and catch up with mother finally. “Hi, Mama, I am tired. I want to eat something!” Mother says :”Oh, kids should not be greedy”

Story 2

This is new year time. An elder and a young are pay a New Year call. Now the elder is saying some auspicious words.

Story 3

The bear dad and mum are looking for their child anxiously. They are talking over where to find their child and dad are comforting mum: “Don’t worry, our honey will be back soon.”

Figure 4-4

[Image removed for copyright reasons. You can view a copy of the image here: <http://www.flonline.de/de/bild-details/2078508.html>]

Story 1

The old man is a birdman. He is going to the forest to find worms with his birds. He is carrying the birdcage with an umbrella because if it rains, it could shade rain.

Story 2

This is a spring day and the leaves are getting green. The old man is going for a walk in a quiet place with his birds, where his friends are waiting for him as well. They chat and the birds sing. They spend a whole morning together.

Story 3

The elders are watching their birds in a park. Suddenly, many other birds fly over. They sing and dance together. A bird fly out and back with another bird. They mated and then a bird baby is born. Now there are many birds in home, where bustling with noise and excitement. The whole family is happy.

Figure 4-5



Story 1

It is a season when rice mature. Some of the peasants are cutting millet, some are tying up, the others are carrying with handcarts.. The peasants are living in the same village and they help each other. Most of the young men are working in the city. The other villagers live on farm and sometimes ask others to help them. After they carry the millets back, they thresh millets and dry them in the sun, finally keep in the band. The rice may be cooled and ate and the straw could be burn.

Story 2

This is a scene of harvest. The peasants of whole village come out and perform their own functions. They cut, tie up and carry crops. They work hard together to send the crops home. They contribute the left rice to country. Only when people have food, could they reach well being.

Story 3

People who work hard are rewarded. They contribute the rest rice to country. They screen the good breed for next year. The great harvest makes people happy.

6 The findings of action research

6.1 The creative storytelling treatment was effective

Table 4-4 and table 4-7 revealed that the people with dementia had been significant higher in attention, expression, interaction, engagement and sharing when pre-intervention compared to post-intervention, although sometimes they presented a low willing to attend caused by amnesia. In addition, the table 4-5 showed more social engagement, general alertness, fewer disengaged and other (neutral) behaviour. As a result, creative storytelling may stir up the people with dementia more active, encourage more frequent interaction with others, thereby brought out wider reaction of recognition and affection.

The table 4-9 told that after TS, the life quality of people with dementia had significantly improved. Also, the interview and observation data showed that the CE storytelling programme played a positive role to raise their quality of life. Nowadays, the people with dementia usually have been restricted by their disease symptoms and security needs. Not only the appropriately inspiring environment, but also activity chance and social interaction are insufficient (Ballard et al., 2001). By means of group activities and one-on-one household visit with families, we developed a social interaction space for people with dementia to take on the role of storyteller and increase communication opportunities. Consequently, life quality is getting better in aspects of external and interpersonal environment. Furthermore, we designed the activity to induce conveying themselves. The elders may enhance their expression and communication by words, at same time, let out internal feelings as well as let down the negative mood. Additionally, on the basis of storytelling, the treatment was receptive and no-critical, there was no wrong answer in their speaking, which thinks highly of the potential creativity and self-esteem so as to make the elders raise the sense of well being as a whole.

However, the result hadn't show a significant change of cognitive function of the participants in the MMSE test. That could be explained by a maintaining effect on the cognitive function of the creative storytelling treatment. Although

there was not statistic meaning of the difference in MMSE score between pre- and post- intervention, a going up tendency after intervention also could present the programme may promote cognitive capabilities to some extent.

Because of impaired cognition, the people with dementia are liable to wallow in stress of reminiscence. However, the storytelling treatment pays close attention to creativity and proficiency via inviting imagination and bring potential creativity into play as a result of boosted interest and engagement along with reduced frustrate feeling. Moreover, to maintain the people with dementia primary cognition, we tried to practice their orientation to time and place through repeated selves introduction, wearing name tags, remind next activities time, blessing festival during activities in advance.

This outcome is in accord with research by Li Guilin (Li et al., 2013) that acceptable individualized intervention, which could satisfy people with dementia physical, mental and social needs may improve quality of life and postpone the progress of disease especially the impaired cognition and mental behaviour symptom. Thus, the creative storytelling treatment is an effective intervention which could advance people with dementia sense of well being by sharing story and preserve function of cognition by simulating creativity.

6.2 The CE storytelling is feasible for Chinese people with dementia

It is always difficult to invite the people with dementia to participate activities due to side-effect of drug, consideration of safety and the symptoms of disease (Williams & Tappen 2007). Therefore we took fully account individual condition in different phase so as to ensure the feasibility of the activities and compliance of participants.

Preparation section comprised organizing and training research team, recruiting and screening participants, planning the action protocol. In terms of research team members, the leader who have epidemiological field study experience and research management capability designed the research proposal which approved by ethical committee of local institution and University of Bath. The members consisted of nursing specialists with rich

experience of dementia care to guide the intervention, well trained facilitators to implement the programme, nurses or students volunteers to assist communication and usual needs like toilet. For participants we have got the support of directors of hospital and nursing home and recruited 31 eligible elders of dementia whose families understood the meaning of research and signed consent inform. With respect to the action plan, the team member discussed and took a full consideration of Chinese culture, elders' individuality and autonomy as well.

Within intervention section, we made great efforts to creating relax and pleasant atmosphere, where the elders were induced to interact and trust each other, meanwhile always gave positive feedback and support to invited creative thinking and promote communication. In addition, regulating mood should be valued as that may let people with dementia gained the sense of fulfillment.

6.3 Key points of the CE storytelling treatment for Chinese people with dementia

The action research explored CE storytelling treatment for Chinese people with dementia and concluded some key points via observation, interview and reflection.

(1) The appropriate number of participants and activity time

Mrs. Basting (Basting, 2011) suggest that a group activities should consist of 6-10 participants, which could be more in case of more facilitators. The programme may be carried out one-on-one as well. With regard to our participants advanced in years, it is difficult to sit for a long time let along concentrate their attention. So in this action research, we implemented the programme by 10-11 persons in each group or one-on -one household visiting for 6 weeks twice weekly and 45 minutes each time.

(2) To choose images

There were some requirements for the images: including the images appearing staged, or that invite a story; the images should not be too busy;

Images can be either B/W or color; Images should be the size of a sheet of regular paper to be easily seen. The training school has a Story Kit of 50 images that is available for ordering. However, except for these requirements, the research team considered the Chinese culture and the education background of the participants and chose some photos from magazines. The images could be a new scene they have never met or seen, but not far away from their life. They also might be a familiar phenomenon but not looked like “real” family photos to prompt reminiscence rather than to prompt imagination. The photos are best not to be weird and tedious otherwise they could say nothing even indulged in a low mood.

(3) Activities facilitation

For the elders have individual characters, it is important to both respect the participants' individual difference and keep on the programme active and harmonious. Only the facilitators well understand the people with dementia and equip knowledge of gerontology, psychology and communicating skill, can they make the best use of circumstance. We are also realising that having a sense of purpose may also be protective against dementia (Buchman 2010). Therefore when we facilitated the activities, we tried to enhance the people with dementia social role and creative engagement, not only to built them learning skills, but also self-esteem and social support.

(4) Activities implementing

The research discovered that repeatedly asking old questions and empty stimulating to people with dementia would lead to a lower satisfaction and heavier psychological suffering (Cappeliez et al., 2005). Our participants, represents most Chinese elderly as their ages, they were heads of the households and masters of work units. On the one hand, they are afraid of losing faces before young people, on the other hand , they are will-less and like following the general trend. So the open-ended questions are about inviting creativity from them rather than a cognitive test, meanwhile , echo each answer to make sure you're getting it right and to let the person know they have been received. Besides, Read all of expressions, such as gestures, sounds and behaviour and validate feelings.

Activities ending: every time, the conclusion and appreciation of may help the participants sharing their achievement again, especially for those who had a great performance .Before the whole programme ending, they always reluctant to part from the group. Therefore we sent presents and took a group photos, or write something on the postcards to alleviate their unwilling to part.

6.4 Advantages of the programme

We conclude following advantages of the CE storytelling programme through observation, interview and reflection

1) To stimulate participants creativity. The facilitators applied images to invite the people with dementia creative thinking and sharing their novel story instead of reminiscent stress.

2) To encourage self expression. During telling creative stories, the people with dementia said their say. There were no wrong answer and no blame echo.

3) To build the self-esteem we believed and find the elders of dementia still keep capacity of development, learning and sharing as long as we give them a social role to play their potential activity and affirm self-worth.

4) In person-centred care, the focus of the care is “centred” on the whole person, not just their symptoms or diagnosis. We employed communicating skill such as the open question and echo the reaction to cause their individual imagination. Also the programme combined the people with dementia with their families and carers so as to promote their understanding each other.

6.5 The localization of the CE storytelling treatment

The Timeslips for people with dementia has been carried on in nursing institutions in American widely. Some experience and evidence by researches is worth considering and learning. However, there is a great difference between Chinese and Western culture result to the difference of attitude, belief, and customs in the intervention. We try to develop a storytelling treatment with Chinese characteristics.

(1) Appropriate images are roots for creative storytelling

In the Timeslips, if stories are the core of intervention, images are carriers of stories. For those people impaired cognition, the photos could be touched and stir up the elders imaging directly, thus make the stories visual and dynamic. In the study, we find that Chinese people with dementia have a different preference of the photos as a result of their different life background, educational level and personal characters. For instance, those who have higher level education were good at anthropomorphizing animals, especially they could grasp the detail of the animals, like eyes, face expression, behaviour. On the other hand, those who received less education tend to express the images combining with their own life experience. In addition, the female participants preferred the pictures which could talk about affection, such as children and family life. On the contrary, the male were inclined to convey the images to personal profession and hot topics.

(2) Felicitously facilitating is support of the storytelling

Apathy, losing initiative, is a normal negative symptom of dementia, which could result in a widely impaired cognitive executive function and some behaviour changes, as low start-ability, disinterest, inpatient (Wang & Zhou, 2003). Therefore, In Timeslips, it is the focus that the facilitators should make effort to lead and illuminate the people with dementia play their imagination, rather than let them indulge in reminiscence pressure. The participants learned that there are no “wrong” answers in Timeslips and all the stories could be different. The further you image, the more splendid the story is. Sometimes the participants talked off the bases or out of the normal rule, blaming may cause anxious, retreat, even conflict or being reticent. So we should listen to them patiently and transfer the topic following their thinking in time. Only like this, may the people with dementia be interested in the activities as well as we develop the application value of the intervention. That is why we say Timeslips storytelling sessions become a “safe space” for people with dementia to experiment with communication. Furthermore, facing the same photo, facilitators should initiate questions considering the difference in education and engagement. For the people with dementia received less education, the

facilitators may use simple word and make some explanation when necessary. For those who were passive in the activity, encouraging, exciting and indicating should keep on used throughout the process. Sometimes the well performers or families also act as facilitators for them.

Chapter 5: Preliminary quantitative research

Preliminary study A: A survey on happiness of elders living in LTC settings

1 Objective

To explore the life quality and its relevant factors of elders living in long term care settings in Fujian, and understand the primary information about the next intervention research sites.

2 Respondents

This investigation purposely selected elders living in 38 long term care settings from Dec. 2013 to Feb. 2014.

(1) Inclusion criteria: the elders who were able to understand, speak and hear mandarin or dialects of Fujian city had willing to participant the investigation.

(2) Sample size: Except for 18 demographic items , such as age, gender, marital status, occupation before retire, etc., Memorial University of New-foundland Seale of Happiness , (MUNSH) was employed which contains 24 items. According to the statistic rules and multiple-factor analysis, the sample size was roughly calculated as 10-15 times 24 items (Fang & Hao, 2001). That is to say the survey needed 210-420 responders. However, 10% of the size to replenish no reply, the sample size reached to 231-462. The survey actually sent and collected 448 questionnaires on spot, among which 421 validated questionnaires account for 93.97% effective rate.

3 Investigating tools

3.1 The demographic data and daily activities survey

16 items of basic information was listed: including age, gender, marital status, occupation before retire, monthly income, family relationship, personal characters, drinking tea, diet control, chronic disease, hobby, engagement to activities held by institution, physical exercise, recreation, admitted time, etc..

3.2 Memorial University of New-foundland Seale of Happiness , MUNSH

The 4-dimension 24-item tools developed by Kozma and Stones, consisting of 5 items of Positive Affective(PA), 5 items of Negative Affective(NA), 7 items of Positive Experience(PE) and 7 items of Negative Experience(NE). Answers “Yes” for 2 point, “Don’t know” for 1 point, “No” for 0 point. The total score= PA-NA+PE-NE, ranging from -24 to 24. To conveniently calculate, after adding constant number 24, the score ranges between 0-24. The Chinese version was interpreted in 1985 and widely used due to a good reliability and validity. (Feng et al, 2013; Wang et al, 2015; Wang et al, 2013).

4 Data collection

We conveniently select 38 LTC settings distributing in 9 areas of Fujian Province to have cross-sectional study for general information and MUNSH score of elders. With support from Fujian Provincial Social Welfare Bureau, who sent introduction letters to local Social Welfare Bureau to explain the purpose and content of the survey. The local officials gave overall information of local long term care situation and recruited institutions willing participant the survey. Then we interview the eligible elders face to face and document the responds. For those who spoke local dialect only, we ask the staff of settings to interpret. The validity of questionnaire was checked as well before the survey ending.

5 Statistic analysis

All the data was recorded and entered into Epidata3.0 software by two persons respectively, which have the function of correcting errors. Then the data was analyzed through SPSS11.5. The frequency and constitute ratio was applied for describe analysis, t test and variance analysis for single factor analysis and stepwise multiple regression to explain the factors which influent the elders’ happiness. A .05 level of significance was used to evaluate group differences.

6 Results

6.1 The general situation

We investigated 421 elders, age 60-101 (80.64 ± 8.467), and the general information as following:

Table 5-1 General Situation of Objects (n=421)									
Items		N	Constituent Ratio (%)	Items		N	Constituent Ratio (%)		
Age	60~	25	5.94	Control food intake	Yes	161	38.24		
	65~	34	8.08		No	260	61.76		
	70~	36	8.55	Hearing	Good	371	88.12		
	75~	97	23.04		General	34	8.08		
	80~	97	23.04	Eyesight	Poor	16	3.80		
	85~	132	31.35		Good	233	55.35		
Gender	Male	210	49.88		General	92	21.85		
	Female	211	50.12			96	22.80		
Marital status	Have spouse	92	21.85	number of chronic disease	No	114	27.08		
	No spouse	329	78.15		1	158	37.53		
Education	Illiteracy	133	31.59		2~	134	31.83		
	Primary school	104	24.70	Hobby	≥4	15	3.56		
	Middle school	127	30.17		No	270	64.13		
	College and above	57	13.54		1	101	23.99		
Former professional	Farmer	118	28.03			50	11.88		
	Workman	150	35.63	Participating in activities held by agency	Never	238	56.53		
	Offical	89	21.14		Occasionally	46	10.93		
	Teacher	39	9.26	Sports activities	Often	137	32.54		
	Medical staff	15	3.56		Basically no	230	54.63		
	Others	10	2.38		Once a week	15	3.56		
Monthly income (RMB)	<1000 yuan	160	38.00			20	4.75		
	1000 yuan~	163	38.72			156	37.06		

	≥3000 yuan	98	23.28	Recreational	Basically no	300	71.26
Family	Poor	35	8.31	activities	Once a week	12	2.85
relations	General	97	23.04		Twice a week	16	3.80
	Good	289	68.65		Once a day	93	22.09
Character	Extrovert	249	59.14	The time of living	<5 years	339	80.52
	Neutral character	79	18.76	in institutions	5 years~	45	10.69
	Introverts	93	22.10		≥10 years	37	8.79
Drink tea	No	276	65.56				
	Yes	145	34.44				

6.2 Evaluation of MUNSH

The survey showed the elders perceived happiness scored 34.19 ± 12.38 , among which the positive affective 7.37 ± 3.07 point, negative affective 2.28 ± 3.03 points, positive experience 9.04 ± 3.99 and negative experience 3.95 ± 4.12 . The positive affective an experience was far more than the negative ones.($P < 0.01$)

6.3 ANOVA of the factors affected elderly MUNSH scores

Those who have poor family relationship, personality introvert, no hobby, never token part in the activities held by the institution, almost or completely no physical exercise have lower happiness.($P < 0.05$)(Table 5-2)

Table 5-2 ANOVA of the Factors that Affect the 421 Elderly Happiness Scores				
Items	Factors	MUNSH Scores ($\bar{x} \pm s$)	F/ t	P
Age	60~	32.19±13.77	F=1.682	0.170
	70~	33.02±13.13		
	80~	35.51±11.06		
	90~	34.68±13.59		
Gender	Male	33.91±11.90	t=-0.463	0.643
	Female	34.47±12.86		
Marital status	Have spouse	34.06±12.44	t=-0.405	0.686
	No spouse	34.65±12.23		
Education	Illiteracy	33.04±12.62	F=0.636	0.592
	Primary school	34.30±12.64		
	Middle school	34.84±11.72		
	College and above	35.23±12.90		
Former professional	Farmer	34.86±12.52	F=2.049	0.071
	Workman	32.83±12.38		
	Offical	33.21±13.02		
	Teacher	39.08±10.17		
	Medical staff	32.87±11.77		
	Others	38.40±9.88		

Personal income monthly (RMB)	<1000 yuan	33.74±13.23	F=0.234	0.792
	1000 yuan~	34.68±11.55		
	≥3000 yuan	34.10±12.38		
Family relations	Good	35.57±11.78	F=11.441	<0.001
	General	33.25±12.02		
	Poor	25.40±14.57		
Character	Extrovert	36.62±11.26	F=13.505	0.000
	Neutral character	32.14±12.02		
	Introverts	29.43±13.89		
Drink tea	Never	33.81±12.57	F=0.438	0.726
	More than one week	34.12±12.30		
	Every three to five days	32.47±12.70		
	Everyday	35.15±12.08		
Control food intake	Yes	34.00±12.58	t=-0.248	0.805
	No	34.31±12.28		
number of chronic disease	No	36.79±11.56	F=2.324	0.074
	1	33.18±13.29		
	2~	33.23±11.56		
	≥4	33.60±13.89		
Hobby	No	32.27±13.07	F=10.644	0.000
	1	36.53±10.12		
	≥2	39.80±10.19		
Participating in activities held by agency	Never	31.78±13.16	F=11.232	0.000
	Occasionally	36.00±9.79		
	Often	37.77±10.76		
Sports activities	Basically no	31.32±12.81	F=10.870	0.000
	Once a week	36.47±10.82		
	Twice a week	33.15±11.37		
	Once a day	38.33±10.79		
Recreational activities	Basically no	32.89±12.62	F=6.653	0.000
	Once a week	36.75±12.28		
	Twice a week	29.63±13.13		
	Once a day	38.85±10.21		
The time of living in institutions	<5 years	33.88±12.34	F=1.136	0.322
	5 years~	34.13±14.12		
	≥10 years	37.11±10.30		

6.4 The stepwise multiple regression analysis for the impact elements which influenced the happiness

6 predictive variables with significant power among 16 predictive variables were physical exercise, personality, family relationship, chronic diseases, hobby, monthly salary. The multiple correlation coefficient between 6 predictive variables and dependent variable "happiness" was 0.442, determination coefficient (R^2) 0.195, the last integrity inspection of the regression model $F=16.749$ ($P<0.001$), so that the 6 predictive variables could effectively explain 19.5% amount of variability. With regard to the rate of contribution, the most significant power was physical exercises, which account for 6.8% variability, followed by personality shared 5.4%, and the other 4 independent variables took up 3.8%, 1.1%, 1.3%, 1.1%, respectively.

Nonstandard regression equation: $\text{Happiness} = 30.911 + 1.863 \times \text{physical exercises} - 3.268 \times \text{personality} + 3.915 \times \text{family relation} - 1.608 \times \text{number of chronic disease} + 2.745 \times \text{hobby} - 1.843 \times \text{monthly salary}$

Standard regression equation: $\text{Happiness} = 0.214 \times \text{physical exercises} - 0.217 \times \text{personality} + 0.202 \times \text{family relation} - 0.110 \times \text{number of chronic disease} + 0.155 \times \text{hobby} - 0.115 \times \text{monthly salary}$

Table 5-3 Summary Table of Stepwise Multiple Regression Analysis

Order of Input Variables	Multiple Correlation Coefficient	R ²	△R ²	F	△F	Regression Coefficients	Standardized Regression Coefficients
						30.911	
1. Sports activities	0.261	0.068	0.068	30.685***	30.685***	1.863	0.214
2. Character	0.350	0.122	0.054	29.091***	25.688***	-3.268	-0.217
3. Family relations	0.400	0.160	0.038	26.513***	18.870***	3.915	0.202
4. number of chronic disease	0.414	0.171	0.011	21.517***	5.643*	-1.608	-0.110
5. Hobby	0.430	0.184	0.013	18.775***	6.641*	2.745	0.155
6. monthly income	0.442	0.195	0.011	16.749***	5.581*	-1.843	-0.115
Notes: *P<0.05; ***P<0.001							

7 Discussion

7.1 Elders living in Fujian Provincial long term care institutions have a relatively high happiness score.

This survey showed the happiness of elders admitted in Fujian provincial long term care institutions is in upper lever, comparatively speaking, which is close to Tangshan, China (33.36 ± 11.45 , $t=1.376$, $P=0.170 > 0.05$)(Li, D. et al, 2013), higher than Fuzhou area(25.65 ± 11.81 , $t=14.153$, $P=0.000 < 0.001$) (Lin, R. et al, 2014) and lower than Beijing(39.30 ± 8.17 , $t=-8.468$, $P=0.000 < 0.001$) (Wang et al, 2013). This results probably may displayed the different attention to the long term care system paid by different local government in China, so as to result in diversity of living environments, health care and so on.

7.2 The happiness of elders living in the institutions approached to those home-bound.

Surprisingly, this survey results closed to the happiness of home-bound elders from Fuzhou, Chongqing and Tangshan , China(Jiang & Lin, 2008; Li, S.Q. et al, 2012; Guan et al, 2007), and higher than some countryside area (24.56 ± 11.61 , $t=15.959$, $P=0.000 < 0.001$) (Hu, J.S. et al, 2006).

Traditionally there is negative impression on elders living in institutions, moreover, the elders and their children are ashamed of it (Shang, 2001). However, more and more urban elderly begin to receive the idea of being cared in institutions, as the percentage reached to 65% responders (Zhan et al, 2006a; Ding et al, 2001; Deng et al, 2003; China news, 2007). The attitude is affected by personal characters, health and community condition, etc. From individual view, the worries about the adaptability to the institutions exist normally, even in those countries or areas where LTC settings have better living condition. Living in institutions may raise psychological stress which is second to divorce and be bereft of spouse (Gordon ,1985)and result in feeling of been abandoned, unreliable, and out of touch with families and friends (Chenitz, 1983; Mikhail, 1992). Most elders are passive and

powerless to make a decision thus lead to their negative feeling to LTC institutions. Abroad research showed that the primary reason to living in the institutions were functional disability or bad health condition (Kwok et al, 1998; Schoenberg et al, 1997). Nevertheless, things are opposite in China, elders in bad health are not willing to living in LTC institutions and those who have plentiful income afford for the LTC institutions ,especially private ones (Zhan et al ,2006a ;Zhan et al ,2006b ;Jiang et al ,2006 ;Kwok et al ,1998). In addition, the attitude to the LTC settings depend on the family relationship, for those who lack of family care and intergenerational support, the LTC settings are better choice. (Schoenberg et al, 1997; Kwok et al, 1998; Brody et al, 1978; Greenberg et al, 1979). On the other hand, social factors such as treatment and living condition, social interaction, social activities held by the institutions are also accounts for non home-bound living (Schoenberg et al, 1997; Jiang et al, 2006). That is to say, the long term care institutions may satisfied the elderly social needs.

7.3 Factors influenced the happiness of the elders living in institutions

The table5-3 displayed the main factors impacting the happiness, as physical exercise, personal character, family relationship, number of chronic disease, hobby and monthly income.

The investigation revealed that the physical exercises, hobbies have a significant influence to the happiness, consisting with previous researches (Zhang, 2011; Wang et al, 2011). Although body exercises may decrease the depression (O'Hartaigh et al, 2014), the elders living in institution seldom do exercises because there have no appropriate space and they are afraid of fall and injury from the exercises. As recessionary physical condition, some elders selected feasible hobbies and recreational activities to kill time (Li, H.J. et al, 2012) and reflect the social value of self. Thus the institutions should carry out some simple body exercises and activities for elderly according to their actual health condition and the institution environment for a happier experience.

The introvert elders and those with poor family relationship, were more

unhappy than others. This may remind the staff of institutions to take care of these elders' characters, interest, needs as well as try to establish an domestically warm environment. It is important to suggest their children to visit their parents rather than telephone connection. Those who have active characters interact even living with the elders who have same interest may release introvert elders' feeling of aloneness (Kwok et al , 1998; Brody et al, 1978; Greenberg et al, 1979).

Besides, the number of chronic disease and economical status also affect their life quality. As the elders who live a healthy and rich life tend to have positive experience, otherwise unfortunate feeling would always dominate their subjective experience (Zhang et al, 2008). Veenhoven (Veenhoven, 1995) and Zhao Hedan (Zhao et al, 2011) believed that ,only for meeting the innate needs, do economy status impact the perceived happy. This prompt the LTC settings to get more support from government and improve medical and nursing quality to lowdown the complication ratio and raise their satisfactory.

7.4 Enlightenment from the survey to the following study.

This survey revealed that the life quality of elders who are living in Fujian provincial long term care institutions are affected by physical exercise , personal characters, family relationship, chronic disease, hobby, monthly income, etc. Another investigation on people with dementia undertook by Wang Zhiwen (Wang et al, 2000) showed their life quality were related with physical function, recreation, social contact and economical status. Additionally, they were not satisfied with sexual life, physical health, recreational activities. Thus some factors play part in normal elders as well as in people with dementia. In addition, Chen Shuhui (Chen, 2005) verified the positive correlation between perceived life quality and cognitive function. Therefore, firstly, it is meaningful for the people with dementia living the long term care institutions and hospitals to carry on some social patients-centered activities. Secondly, the research design and implementation should pay more attention to the factors which would influence the elders perceived life quality.

Besides, among 421 investigated elders, 188 elders living in public LTC settings vs 233 cases in private settings. The MUNSH score and Positive Experience score between the two groups had not significant difference ($Z = -0.377$ 、 -1.264 , $P > 0.05$) . But there existed statistic different in Positive Affection score($Z = -2.442$, $P < 0.05$; $M_{Private} = 9.00 > M_{Public} = 8.00$). Another survey on the treatment environment for people with dementia in Fujian provincial LTC settings revealed that there was no disparities between public settings and private ones(Li, 2015). Those data may be an useful evidence for the grouping of following study.

Preliminary study B: A pilot study to evaluate the TimeSlips

1 Purpose

As there is not any allied research in Chinese and the mean and standardized difference of indicators could not be found from previous study. To calculate the sample size of evaluation study accurately, a 16-sample pilot study was undertaken three months ago.

2 Participants

We purposely chose 16 cases of people with dementia as participants, who admitted in geriatric wards of Fujian Provincial Hospital for several years, including 14 men and 2 women, with age of 84-95. The participants were informed the meaning of the study, the proved benefit, process and time of the programme, as well as our promise to harmlessness, privacy protection, etc. and then signed the informed consent.

3 Interventions

We employed the revised protocol of TimeSlips to undertake intervention, which lasted 30 -60minutes every time twice weekly for 6weeks. The pilot study was conducted in the activity room of geriatric ward in Fujian Provincial Hospital. The research team consisted of a facilitator, 12 companions, a person who writing on the white board, 2 recorders and 3 persons responsible for taking photos, video and audio data.

4 The evaluating indicators

We measured and collected data of MMSE, QOL -AD before and after the intervention.

5 Statistic analysis

The data was put into SPSS on version 11.5 for windows. T test analysis was performed, and $P < 0.05$ level of significance was used to evaluate the group difference.

6 Results

Table 5-4. The Statistical Description of MMSE Scores before and after the Intervention

Items	n		
MMSE Scores before Intervention	16	18.250	4.219
MMSE Scores after Intervention	16	20.880	4.853

Table 5-5. The Statistical Description of QOL-AD Scores before and after the Intervention

Items	n		
QOL-AD Scores before Intervention	16	28.750	5.556
QOL-AD Scores after Intervention	16	30.060	4.464

Table 5-6. Paired Samples t-test

Items	Mean d	SD	T	p
MMSE (n=16)	3.063	4.057	3.019	0.009
QOL-AD (n=16)	-1.313	4.012	-1.309	0.210

7 Conclusion

The pilot study showed a significant improvement in MMSE score, whereas no obvious difference in QOL level before and after intervention. Firstly, it initially revealed the intervention effective in cognitive competence Secondly, the small sample number and short time intervention may not cause the change of life quality at once, that is to say, in the following formal research we should try

to increase sample size and retest the indicators one month after intervention. Thirdly, the 16-participant group is too large to let the participants express their story adequately. Fourthly, we could reduce the personnel of research team in the later research to increase the efficiency of the research members.

Preliminary study C: Development of Chinese version FACS

1 Objective

The purpose of was to determine the reliability and validity of the Chinese Version of the Functional Assessment of Communication Skills (CV-FACS) which was formulated based on the two Subscales of the Functional Assessment of Communication Skills (SFACS). Meanwhile, the applicability of CV-FACS in China was evaluated in people with dementia.

2 Method

FACS was developed by Frattali et al in 1995 and used for aphasia patients initially, afterwards it was widely applied to assess other patients suffering from dementia, stroke and traumatic brain injury. The scale consists of four subscales: social communication (21 items), communication of basic needs (7 items), reading, writing, number concept (10 items), daily planning (5 items). Each subscale has four qualitative dimensions: adequacy, appropriateness, promptness, communication sharing. Totally, there are 43 items rating 7-point and it is expected to be completed within 20 given minutes. The higher scores are, the better communication ability of subjects will be, and it is assessed by medical staffs, family members or caregivers who contact with the patients regularly.

The reliability and validity of the scale are described as follows: (1) Inter-rater reliability ranged from 0.72 to 0.92. (2) Internal consistency reliability was 0.82. (3) By the standards of "The Western Aphasia Battery Aphasia Quotient", "State University of New York at Buffalo Research Foundation", "Scales of Cognitive Ability for Traumatic Brain Injury", the Criterion related validity was 0.73, 0.72 to 0.86, 0.78 respectively. We bought a book with legal version (Functional Assessment of Communication Skills for Adults) from America, containing the scale with complete content, detailed instructions and the development process, enclosed a letter of authorization.

(1) The cross-cultural adaptation of the scale

The cross-cultural adaptation study is used to encompass a process that looks at both language (translation) and cultural adaptation issues in the process of preparing a questionnaire for use in another setting (Beaton et al., 2000). In order to attain the equivalence between the original FACS and the Chinese version, we conduct a set of standardized guidelines for the cross-cultural adaptation process, by using translation, back-translation techniques and committee review, especially modifying the items not consistent with Chinese cultural background and customs.

A panel of 10 experts specializing in medical treatment, nursing care or LTC institutions management was selected to assess the semantic, idiomatic, experiential, and conceptual equivalence of FACS and CV-FACS. Two rounds of expert consultation were completed with two weeks interval by E-mail questionnaire. Thus, the Chinese Version of the Functional Assessment of Communication Skills (CV-FACS) was developed initially.

(2) The evaluation of reliability and validity

By convenience sampling method, 128 cases of people with mild and moderate dementia, selected from hospitals, LTC institutions between the period from January to March in 2014, were assessed with CV-FACS, aiming to evaluate the construct validity and internal consistency of the scale.

3 Results

(1) Expert consultation

a. Consistency of expert opinions

Variation Coefficient (CV) was used to calculate the coordination degree of the experts' opinions. The Kendall concordance coefficient of each round ($W=0.352$ and 0.200) indicated that the consistency of expert opinions was statistically significant ($P < 0.05$).

b. Concentration of expert opinions

The items (importance mean < 3.5 , coefficient of variation > 0.25), which were unclear, difficult to express or unsuitable to Chinese customers, were deleted

or revised by the experts. As a result, the initial Chinese Version of the Functional Assessment of Communication Skills (CV-FACS) with 21 items was deemed appropriate for further testing and analysis.

(2) Reliability and validity testing

a. Content validity

Content validity index (CVI) of the CV-FACS was 0.91 on average (Range: Min=0.78, Max=1.00), indicating that this scale had good content validity.

b. Construct validity

KMO index=0.86 from the Bartlett's Test indicated that this dataset could be applied into EFA. Two factors were selected according to the principal components analysis with the criteria of Eigenvalue >1, which was consistent with the original scale. The correlation coefficient for each factor and the total scale was 0.84 and 0.69 respectively, and the correlation coefficient for the two dimensions was 0.68. Each item and its corresponding dimension ranged from 0.406 to 0.751, indicating that internal homogeneity of each dimension was good, as well as showing that the CV-FACS had good construct validity.

c. Internal consistency reliability

Internal consistency reliability by Cronbach's α was 0.930 and that for two dimensions were 0.922 and 0.797, respectively, indicating that the CV-FACS had good internal consistency reliability.

d. Test-retest reliability

The scale was retested after two weeks later by assessing 10 cases of people with mild and moderate dementia. The Pearson correlation coefficient for the two tests was 0.839, indicating that CV-FACS represented good stability and reproducibility.

e. Inter-rater reliability

14 cases of people with mild to moderate dementia were evaluated by two different assessors within 24 hours. The Pearson correlation coefficient was 0.606, indicating the CV-FACS had good inter-rater reliability with objective

scoring.

4 Conclusions

Adaptation of FACS for use was achieved by designed process of cross-cultural study, ensuring the semantic and conceptual equivalence between the CV-FACS and the original one. It can be adapted culturally with demonstrated good reliability and validity.

Chapter 6: The evaluation quantitative research

1 Research question

The researches have verified the effectiveness of non-pharmaceutical therapy and developed CE storytelling treatment. We have finished the action research and modified the Chinese CE storytelling programme. Whether the treatment would change the condition of people with dementia, as cognitive recession, quality of life, communicating ability and mood was uncertain.

2 Research objectives

The aim for the quantitative research is to implement the final CE programme and evaluate the effectiveness of CE in people with dementia of Fuzhou.

- (1) To evaluate the effectiveness of TimeSlips to the communicating ability of people with dementia.
- (2) To evaluate the effectiveness of TimeSlips to the mood status of people with dementia.
- (3) To evaluate the effectiveness of TimeSlips to alleviate the depression of people with dementia.
- (4) To evaluate the effectiveness of TimeSlips to maintain the cognitive competency of people with dementia.
- (5) to evaluate the effectiveness of TimeSlips to the life quality of people with dementia.

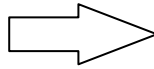
3 Research design

We purposely screened the people with dementia from elderly words and nursing homes. We divided the samples into test group and control group. The test group received TimeSlips intervention. To rule out the possibility that any improvements observed in participants were due to the received attention during TimeSlips activity, a social contact condition was developed and implemented in control group. After intervention, the ability of communication, cognition, mood, depression and life quality were evaluated.

Independent variable

Dependent variable

**Timeslips
intervention**



Control group

Difference in the level of
Cognitive Competence
Communication skills
Quality of Life
Emotion
Depression

Figure 6-1

Statement of Hypothesis

After TimeSlips intervention for people with dementia,

- (1) There is a significant difference in the level of cognitive competence of the respondents.
- (2) There is a significant improving in the level of quality of life.
- (3) There is a significant increasing of communication capability.
- (4) There is a significant decreasing of depression.

4 Research methodology

4.1 Participants and recruitment

4.1.1 The resource of the participant

Because the leader of research worked in Fujian Provincial Hospital, for the convenient research management we recruited part participants from the geriatric wards of this hospital and its affiliated hospital, Fujian Provincial Geriatric Hospital. By Chinese traditional culture, the elders would rather live in homes with their children than being admitted to nursing institution although they have lost their life independence. We have undertaken a survey to 45 nursing homes which admitted people with dementia in Fujian Province and assessed their treatment environment for people with dementia (Li Hong, 2014). There are 7 public and private nursing homes admitting people with dementia in Fuzhou city, from which we purposely chosen 4 institutions: 2 public social welfare houses and 2 private nursing homes. Where have been

assessed to provided qualified treatment environment for people with dementia. Also support of the directors of these institutions was acquired. To minimize contamination of the intervention's effectiveness, we assigned individual facilities to either control or intervention status (rather than having both within each facility). However, at times, facilities were not assigned randomly because of concerns about potential imbalance of group sizes.

4.1.2 Criterion of the dementia diagnosis

The diagnosis criteria for the dementia complied with WHO international classification of diseases (DSM-4 ICD-10) (World Health Organization, 2008).

Memory impairment is often a prominent early symptom. Individuals with dementia have difficulty learning new material. These short-term memory problems commonly result in losing valuables or non-valuable. In more severe dementia, individuals also forget previously learned material. Not only the people with dementia main complain but also objective assessment to symptoms above.

The history and neuropsychological test may explicit the cognitive impairment and disorder of thinking and judgment.

Cognitive deficits must be sufficiently severe to cause impairment in occupational or social functioning, mood, engagement and must represent a decline from a previous level of functioning.

The clinical symptoms of impaired memory and cognition have appeared for more than 6 months. The symptoms as alogia, agnosia and aphasia remind an injured cerebral cortex, which could more supportive to the diagnosis. Imaging examination, including CT、MRI、SPECT and PET may have relative changes.

(1) Inclusion criteria

a. A dementia diagnosis.

b. A Mini-Mental State Examination (MMSE) (Folstein et al., 1975) score of ≥ 11

but ≤ 26

c. The ability to understand and speak mandarin or dialects of Fuzhou city, hearing adequate to hear the programme dialogue, eyesight adequate to view the programme stimulus picture.

(2) Exclusion criteria

a. With a Cornell Scale for Depression in Dementia (CSDD) score > 12 , indicating severe depression (Alexopoulos et al., 1988; Watson et al., 2003)

b. With advanced terminal illness

c. Displaying behaviour that would make interview impossible, such as constant wandering, shouting, or aggression

d. Having a diagnosis of learning disability

In terms of the cutoff score for screening and distinguishing from mild to moderate dementia, there is not yet a general consensus on the criteria due to different culture, region and other demographic characters. Mini-Mental State Examination (MMSE) (Folstein et al., 1975) is usually employed to divide the mild and moderate dementia stage, by which the cutoff score between 19 and 24 is used by many foreign researchers. However, for Chinese people, a multicentre survey was carried out by Peng (Peng, 2005). 2084 subjects, including 40-year older normal subjects, dementia, obscure disease in Beijing was investigated with MMSE. The result showed a cutoff score of MMSE checked dementia in Chinese population, like a higher education the higher score was used to cutoff the dementia, that is illiterate group was ≤ 24 and cultural group (primary school -) was ≤ 26 . Meanwhile, the cutoff score of dementia between mild and moderate dementia, illiterate group was ≤ 17 point, cultural group ≤ 19 point. MMSE. For this study, MMSE score ≥ 19 and ≤ 26 was applied as the cutoff score.

(3) Elimination and withdraw criteria

a. person could not continue to the programme due to exacerbation of dementia symptoms or other disease ;

b. bad compliance.

c. died, discharge or check out from the institute.

4.1.3 Recruitment strategy

(1) People with dementia

Support for the study was received from health and social care organizations in Fuzhou. Participants will come through rest home centres, and geriatric wards in hospitals in Fuzhou. A prepare meeting was arranged with the manager. In the meeting, the inclusion criteria were used to select possible participants, who were then approached by us with information about the project.

(2) Nurses

In the beginning of the recruitment process all members of nurses will be informed of the planned process. A written information leaflet delivered to each member outlined the aims of the study, given an overview of the research approach and invited each member to register their interest. The same information will also be delivered through oral presentations at morning meetings. We will emphasize that participation in the study is voluntary and that participation or non-participation will have no effects on the professional development. We aim to recruit at least 5 to 10 nurses each health facility to take part in Phase2 research.

4.2 Sample size

We decide to use a t- test sample formulation to calculate the sample size (Zhou & Sun, 1999)

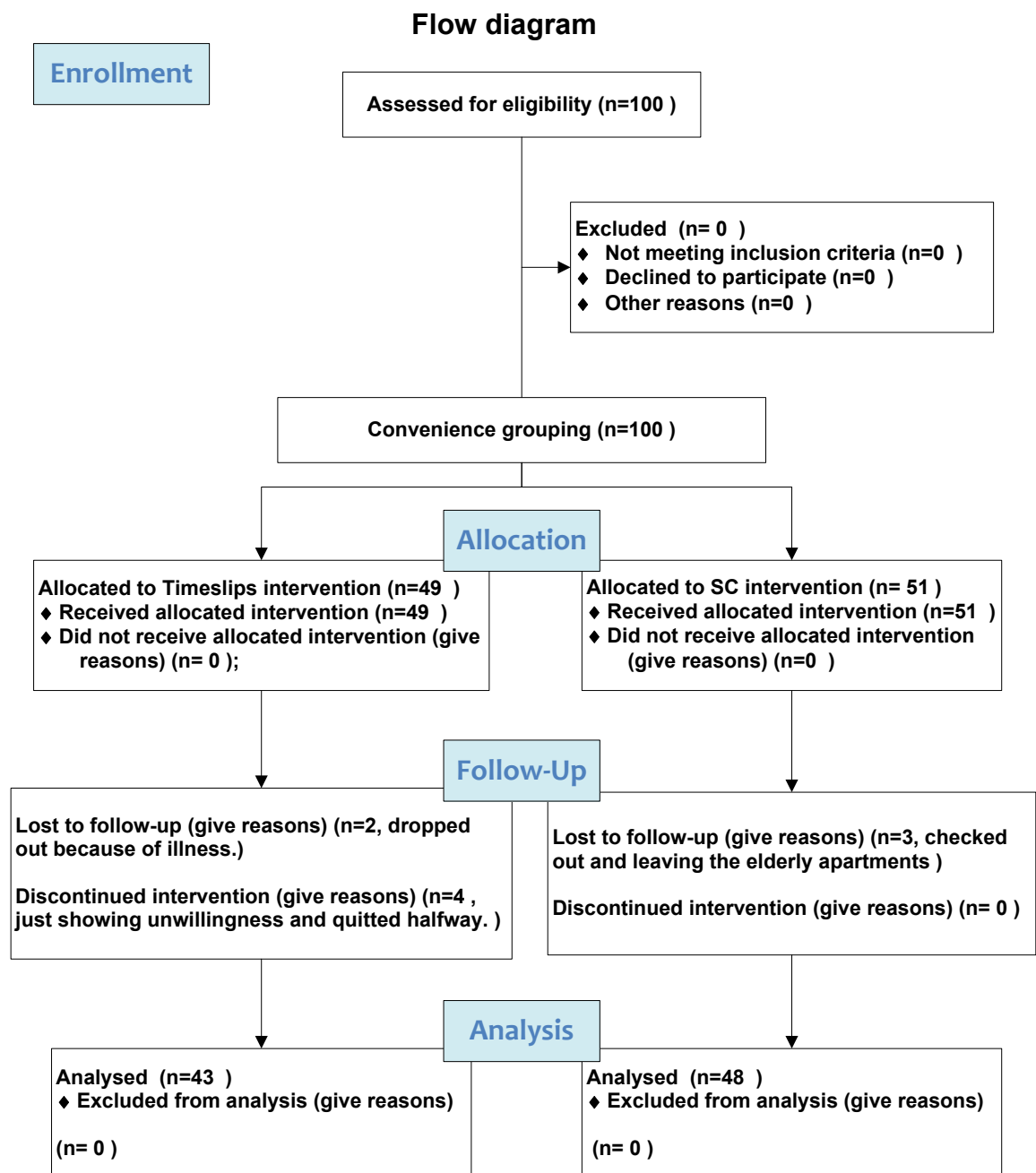


We could not acquire the mean and standardized difference of indicators from previous study because there is not any allied research in Chinese. We have done a 16-sample pretest pilot three months ago. (Pretest A). We chose $\alpha=0.05$; $\beta=0.10$; accordingly [REDACTED], [REDACTED]. According to the pretest pilot study, the “the language ability” of MMSE pre and post difference: $\delta=0.937$, $\sigma=1.204$, so that the single group sample would be 35. In view of

10% attrition rate, the two groups sample size could reach 78 totally. We have recruited 91 participants, 43 cases in treatment group and 48 cases in control group.

4.3 Grouping

We conveniently selected participants from Fujian Provincial Hospital, Fujian Provincial Geriatric Hospital, Fuzhou First Social Welfare Home into testgroup, and those from Fuzhou Anxin Nursing Home, Xiyanghong Elderly Apartment, Taijiang Elderly Apartment were distributed to control group. The control group participants were from the private settings.



4.4 Intervention

4.4.1 The demographic investigation

The demographic data form (appendix I) included age, gender, education background, marital status, retired occupation, monthly income, self- care ability, etc.

4.4.2 Intervention

The two groups were equally received normal treatment and care. The

testgroup was delivered revised TimeSlips intervention while the control group was undertaken social contact activities. Data form both of them collected for 6 weeks.

(1) Assessing before the activity

1) Participants:

Every activity may group 6-10 elders with dementia, more participants in case of more facilitators.

2) Assessment

To collect the baseline condition the facilitators should consult from the charts, communicated with the people with dementia, families, care givers and primary nurses. The data comprise disease condition, communicating ability, educational level, characteristic, interests, etc. Also physical and mental state before and in the course of every activity should not be overlooked.

3) Activity time and duration

At each turn, the activity may take 30 minute to 1 hour. It is important to consult the people with dementia and care givers of their activity time to avoid conflicting with their treatment plan and daily schedule.

(2) Preparation for the activity

1) Implementers:

The conductors were ready for their responsibilities. The programme at least need 1 facilitator who invite and lead the storytelling, 1 recorder to write down all the answers and responds on the whiteboard with a marking pen. Beside, some assistants or care givers are needed to help the elders communicate, go to toilet and other demand for operability and safety. In the study period, to get an accurate data, the assistants are research team member.

2) Site and space preparation

To ensure the site is easily accessible to. The space should be relatively bright and quiet without distractions. It is better to put the chairs in a semi-circle and enables the group to see each other, leaving space between them in case the facilitators need to move right next to someone in order to be heard.

3) Materials

Some materials should be prepared, such as images, name tags, markers, white board or paper big enough to be seen, microphone if necessary. The image is the core of the activity. There are some requirements for the images: ①images can invite a story; ②images should not be too busy; ③images can be either B/W or color; ④images should be the size of a sheet of regular paper to be easily seen. However, except for these requirements, the facilitator had to consider the Chinese culture and the education background of the participants to choose some photos from magazine or internet. The images could be a new scene they have never met or seen, but not far away from their life. They also might be a familiar phenomenon but not looked like “real” family photos to prompt reminiscence rather than to prompt imagination. The photos are best not to be weird and tedious otherwise they could say nothing even might indulge in a low mood. In this study 12 images were kept to the photo kit.

(3) The process of the activities

1) Preliminary stage

①Every time before the intervention, the implementers invite the participants initially and remind them to bring glasses and hear-aids, and then wearing their name tags.

②Welcome the storytellers to the activity.

③The facilitator introduce him/her self and the activity purpose and meaning as well as process. The first time should be given more time for the participants to know each other well. Some calm and leisurely old songs may promote emotional communications.

④Review the story from the previous session.

This step may help the participants remind the process of the activity and understand their role of activity again.

2) Main stage

① Select a new image

Before the start, the elders could select an interesting photo from 2-3 prepared images and every participant owned a same image every time so as to keep it in mind.

② Ask open-ended questions.

The facilitator applied “open-ended” question to encourage imagination and individual expression. The questions could be 5W1H, (When, Where, Who, What, Why and How), which related to the image content directly. Besides the questions could also jump outside the image but relevant to the theme. Meanwhile, the assistants convey the information repeatedly and timely in order to avoid ignoring anyone.

③ Echo all responses and retell the story

The implementers try to write down all responses to let the storyteller know they had been heard and understood. In necessary, retell the story purposefully to refocus the storytellers. The facilitators should equally keep a watchful eye on every participant rather than only some outstanding performance.

④ Build to a final retelling.

To weave and share the story again, the facilitator state the whole story and try to give a topic of the story.

3) Ending stage

① When the elders feel tired of the storytelling, the facilitator concludes the activity in time. Then appreciating the elders’ engagement and praising the outstanding performance.

② To remind the time and site of next activity

③ To say good-bye to the elders.

④ To reflect and conclusion activity every time to improve the programme.

4.4.3 The research team and their responsibility

The intervention team consisted of 12-15 members.

(1) 1 facilitator, held the whole process of the CE storytelling activities, consisting of introduction of the programme, asking open-ended questions, echoing the respond of the participants, retelling and concluding their stories.

(2) 3-6 companions: (2 people with dementia to 1 companion), taking part in the implementation of the programme, as accompanying with the people with dementia from and back their rooms, helping toilet and other demanding of the people with dementia. During the activities, they tried to attract elders attention and assist communication, like repeat the talk of facilitator and other people with dementia to the assigned people with dementia as well as repeat the talk to the group in necessity.

(3) 1 recorder who writing on white board. write down all the answers and respond on the whiteboard with a marking pen so that the facilitator and elders could recall what they have talked.

(4) 2 recorders: Integrally and accurately recording the process in detail. And the focus is what the people with dementia said.

(5) 1 person for data collection: handing out the images and questionnaires before the activity. When the activity ending, he should collect the data, and give feedback to PI in case of wrong and missing data.

(6) 3 persons for photograph, audio and video.

(7) 1 field staff to arrange the activity site and time; assign other members, prepare the materials, solve something emergency to ensure the activities undertaken smoothly.

4.5 Control group activities

Considering the test group might have a Hawthorne effect, the participants in

control group received social contact programme (Social Contact, SC). Ronald (Ronald et al., 1997) has concluded the general social contact is comprised of 8 kinds of activities: music, art, literature/writing, dance/exercise, play game, festival or activity planning, discussion and so on. We designed the social contact programme as following:

(1) 0min~: Welcome to the participation.

(2) 4min~: Orientation for time and place.

(3) 8min~: Songs in chorus.

(4) 20min~: Main part: including self-introduction, recall memorable events, appreciation music or documentaries, tangram puzzles, games (such as origami, maps, shovel beans, fishing, etc.), finger exercises, storytelling or reading newspapers, event planning, etc.

a. appreciation music: "Jasmine", "Swan", "Edelweiss", "Green Sleeves", "Walking in the rain", "Full Moon", "Ode to Joy", "Nanniwang", "Olive Tree", "Miss His Comrades", "Beijing Welcomes You", "Sunny Ninety-nine", etc.

b. appreciation documentaries: "A Bite of China", "The White-haired Girl", "Founding of the Republic", etc.

(5) 55min~: Confirm and remind participants the time and content of the next activity

(6) 58min~60min: Thanked.

To ensure the equal attention, the activity arrangement of testgroup is similar with the control group in frequency, duration, interval time, number of participants each time. In addition, the facilitators were non-interfering, that is they did not participate another activity.

4.6 Evaluation indicators

4.6.1 Mini-Mental State Examination (MMSE)

To compare the effect of CE storytelling on cognitive function, we used Mini-Mental State Examination (MMSE) (Zhang, Z.J., 2005) to test participants

at the week0, week7 and week10.

Mini-Mental State Examination (MMSE) was an initiative and brief cognitive test tool developed by Folstein in 1975 (Folstein et al., 1975) (Appendix V). MMSE has a good reliability with ICC 0.99%, 48-72 hour retest ICC 0.91%, and the related validity WAIS (Wechsler Adult Intelligence Scale) is high. It is widely used in the world. There is two Chinese version with a good reliability. This study used Chinese version by Zhang Mingyuan. It is an 11-item clinical assessment of global cognitive function. The test covers a variety of cognitive domains, such as orientation to time and place, short- and long-term memory, registration, recall, constructional ability, language, and the ability to understand and follow commands. The maximum score is 30. (Appendix V). Every question scores 1 point. The higher points, the milder impaired cognition.

Table 6-1. Interpretation of MMSE Scores	
Score	Degree of Impairment
27-30	Questionably significant
20-26	Mild
10-19	Moderate
0-9	Severe

4.6.2 Quality of Life-Alzheimer's Disease (QOL-AD)

The QOL-AD, developed by Rebecca G. Logsdon from Washington University in 2002 (Logsdon et al., 2002). It is widely used for evaluating life quality of people with dementia. The brief and self-report questionnaire has 13 items covering the domains of physical health, energy, mood, living situation, memory, family, marriage, friends, chores, fun, money, self and life as a whole. It has good internal consistency, validity and reliability (Logsdon et al., 1999). The tool was designed specifically to obtain a rating of the Quality of Life of people with dementia from both the people with dementia and the caregiver. It was developed for people with dementia, based on people with dementia,

caregiver, and expert input, to maximize construct validity, and to ensure that the measure focuses on quality of life domains thought to be important in cognitively impaired older adults. It uses simple and straightforward language and responses assessments of the individual's relationships with friends and family, and staff as well as physical condition and mood. The tool rated on a four point scale, with 1 being poor and 4 being excellent. Total scores range from 13 to 52. It generally takes caregivers about 5 minutes to complete the measure about the people with dementia; for people with dementia, the interview takes about 10 to 15 minutes to administer. (Appendix VI) The Chinese version has been verified to meet the psychometrics criteria (Ai, Y.M., 2011).

In this quantitative research, we collected the QOL-AD data in week0, week7 and week 10.

Table 6-2. Interpretation of QOL	
Score	Interpretation
13.00-25.99	Poor
26.00-38.99	Fair
39.00-51.99	Good
52	Excellent

4.6.3 Cornell scale for depression in dementia (CSDD)

The scale was developed by Alexopoulos in 1988 (Alexopoulos et al., 1988). There are 5 factors in CSDD Scale: mood-related symptoms, Behavioural disturbances, Physical signs, Cyclic functions and Ideational disturbances. It includes 19 items with a total score ranging from 0 to 38, each of which is scored in three levels according to the severity of the symptoms (0 score for “no symptom”, 1 score for “mild or intermittent symptoms”, 2 scores for “severe symptoms”). The higher the score is, the more severe the depression is (He, 2014). The data collected through interview of the people with dementia or

their care givers to evaluate the condition of the people with dementia within nearest week. The interview time usually did not exceed 30 minutes.

We measured the depression symptom changes at week0, week7 and week 10.

4.6.4 The Functional Assessment of Communication Skills (FACS)

FACS was developed by Frattali et al in 1995 .The scale consists of four subscales: social communication (21 items), communication of basic needs (7 items), reading, writing, number concept (10 items), daily planning (5 items). Each subscale has four qualitative dimensions: adequacy, appropriateness, promptness, communication sharing. Totally, there are 43 items rating7-point and it is expected to be completed within 20 given minutes. The higher scores are, the better communication ability of subjects will be, and it is assessed by medical staffs, family members or caregivers. We have developed the Chinese version authorized by the author in the preliminary study. It can be adapted culturally with demonstrated good reliability and validity, as CVIof the CV-FACS was 0.91 on average, the internal consistency reliability by Cronbach's α was 0.930, Test-retest reliability was 0.839, The Pearson correlation coefficient was 0.606.

We assessed the communicating capacity of the participants at week 0, week7 and week 10.

4.6.5 Observed Emotion Rating Scale (OERS)

OERS Scale, a scale for observation, includes 5 items: pleasure, anger, anxiety/fear, sadness and general alertness, of which pleasure and general alertness belong to the positive emotions, while the remaining three are negative ones (Lawton et al., 1999). The emotional states of patients during their eating before and after the intervention are observed for more than 10 minutes in this research. Every item is rated by 6-points:

1 point for never, 2 point for <16 seconds, 3 point for 16-19 seconds, 4 for 1-5

seconds, 5 point for >5 seconds, 7 for not in view. The higher the score is, the longer duration of the mood expression is.

We observed the emotion status of the participant at week 3 and week 6.

4.7 Data Collection

4.7.1 The questionnaire survey

The survey conducted by the trained research members at specific time. The investigators explained the meaning of research purpose and requirement of responding. The investigator inquired the participants by each item of the questionnaires and marked the answers in the questionnaires. The informant could write down the answers by themselves either and the investigators collected and checked the questionnaires.

4.7.2 Standard observation

Observation method acquired first hand data by means of watching carefully and inspecting an event or phenomenon. The observable phenomenon includes: personal characters and status, activity pattern, verbal and non-verbal communicating behaviour, skill proficiency, environment feature and so on. Observation method is always used in case of immeasurable situation, which is widely employed in data collection for nursing research. In this study, we applied structural standard observation to survey the mood of participants in CE storytelling environment with duration of 10 minutes.

4.8 Data analysis strategy

4.8.1 To develop data base. Data were entered into a computer database for analysis using SAS v11.5 software. Data were checked for accuracy and completeness, inconsistencies to protect privacy, and double entered to minimize data-entry errors. All the data was recorded and verified double person by Epidata3.0 software.

4.8.2 Descriptive statistics analysis. Descriptive statistics strategy was used to represent a demographic profile and changing tendency of the indicators for

the outcome measures (i.e., MMSE, CSDD, FACS, QOL-AD, and OERS).

4.8.3 Comparison strategy. A .05 level of significance was used to evaluate group differences at Week 0, Weeks 7 and Week 10 for the variables Of MMSE, CSDD, QOL-AD, and OERS. The standardized mean difference statistic (Cohen, 1988), was calculated in two ways:

(1) to divide the difference between the intervention and the control groups mean values at Week 0, Week 7 Week10 by the pooled SD

(2) to divide the difference between the intervention and the control groups mean change scores (Week 10, Week 7, Week 0) by the pooled SD of the change scores. If one variable was normally distributed, then we used paired t tests to evaluate the mean change at both pre- and post session. If one variable was not normally distributed at either pre- or post-session, then we used the Wilcoxon signed rank test to evaluate the mean change.

4.8.4 Repeated measures analysis of covariance

A repeated measures analysis of covariance comprised of two factors: group and time with the baseline value of the outcome measure as the covariate. The method could compare changes of each dependent variable in the two group respectively during different time period.

4.8.5 Chi-square tests. Observational data on staff – resident interactions and resident engagement were analyzed by conducting independent chi-square tests.

4.9 Quality control

There are 9 quality factors will be considered during quantitative phase design: randomization, allocation concealment, inclusion/exclusion criteria specified, similarity of groups at baseline, assessors blinded to outcome, characteristics of participants lost to follow-up described, intention-to-treat analysis, power calculated and outcome measures valid. According to those standards, we reflect the research quality control.

(1) We consulted the literatures and considered actual practice with help of experts to verify the project scientific and feasible. Moreover, by means of action research and pretest study we ensured the practice- based intervention.

(2) The main confounding factor is that intervention would be not conducted according to a standard pathway. We recruited and trained facilitators. Each group has facilitator and other assistants. This enables the intervention follow a standard pathway. The facilitators not only trained the TS but also the relevant knowledge of gerontology, psychology and pedagogy so as to master the method and main points of the CE storytelling treatment. The facilitators trained the research members by 3 courses as well:

The first class was for the definition and prevalent of the dementia; the meaning of the CE storytelling; the second class trained the content and test skills of the questionnaires and tools. Especially they learned how to use the standard instruction. And in the last class, they trained the method, process, main points, assignment and responsibility, daily care techniques, etc.

(3) Secondly, the participants allocated to the control group receive treatment as usual. This can vary between and within hospitals and rest homes and may change over time, but in principle, the social contact offered to those group either. Besides, we will monitor whether control groups are receiving alternative interventions in this way equally.

(4) Provision for dealing with attrition and promotion of attention: Inform the participants the aim of the research 1 month before intervention. Give incentive strategy such as timely comments, sending flowers or little articles for daily use to those who attend every time. No punishment for those dropping off. We tried to adjust every activity to the elders daily schedule.

(5) As a cross-culture research, every instrument for evaluation should be translate into Chinese version and should be tested reliability and validity.

(6) Another aspect of minimizing bias is data analysis. The series of steps was taken to check the validity of the quantitative data and accuracy of qualitative findings. We applied pre- and post-intervention comparison as well as parallel control design.

5 Results analysis

5.1 Data on social demography

100 cases of people with dementia in total, mild or moderate, are selected by the criteria for proper objects of study among the following hospitals: Fujian Provincial Hospital, Northern District of Fujian Provincial Hospital (Fujian Geriatric Hospital), Fuzhou Social Welfare Home chi-square tests., Fuzhou Anxin Nursing Home, Fuzhou Xi Yanghong Elderly Apartment and Fuzhou Taijiang Elderly Apartment. Among them, 9 dropped out of the study during the process, which means the drop-out rate is 9%, 2 of whom dropped out because of illness, 4 just quitted halfway in the test group, and 3 in the control group checked out halfway (leaving the elderly apartments). The final samples are 91 cases, 43 of which are in the test group and 48 in the control group.

There are 19 male cases and 24 female cases in the test group, with ages of 85.30 ± 5.886 years old, while in the control group, 15 cases are male and 33 cases are female, with ages of 83.46 ± 8.108 years old. There are no statistically significant differences ($P = 0.203, 0.462, 0.099, 0.082$) of genders, educational levels, marital statuses, self-care situations between these two groups, which are regarded to be comparable. (Refer to Table 6-3)

Table 6-3. Comparisons of Data on Social Demography between the Test Group and the Control Group

Types		The Test Group	The Control Group	P
Gender	Male	19	15	0.203
	Female	24	33	
Education	Illiteracy	1	4	0.462
	Primary School	9	12	
	Secondary School	23	25	
	Technological Academy or above	10	7	
Marriage	Married	10	4	0.099
	Single	0	1	
	Widowed	33	43	
Self-care	Fully Self-cared	13	15	0.082
	Partially Self-cared	22	31	
	Totally Incapacitated	8	2	

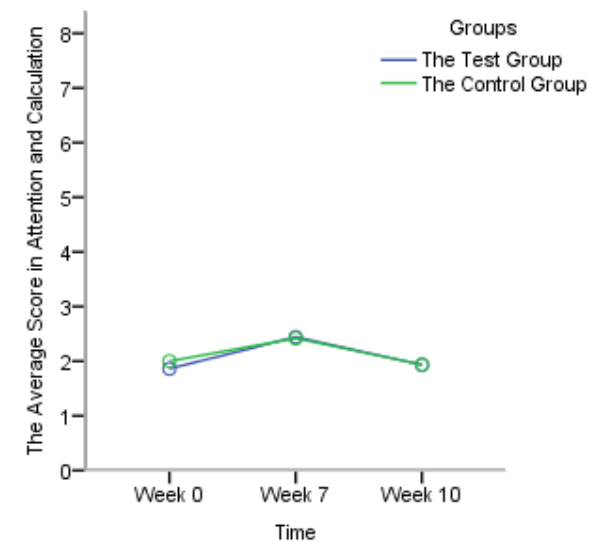
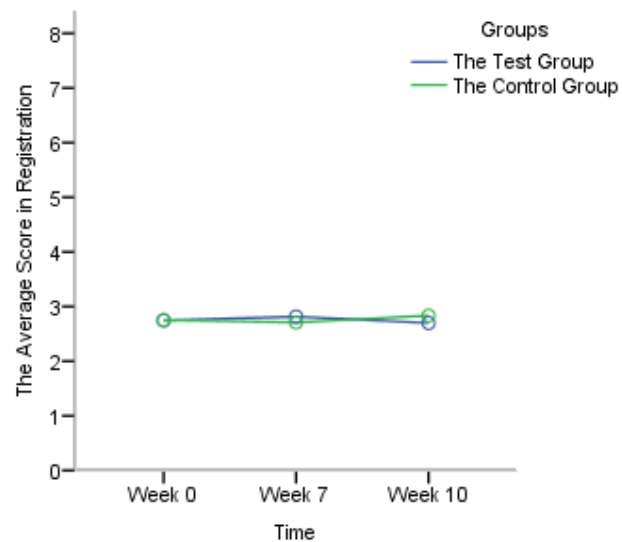
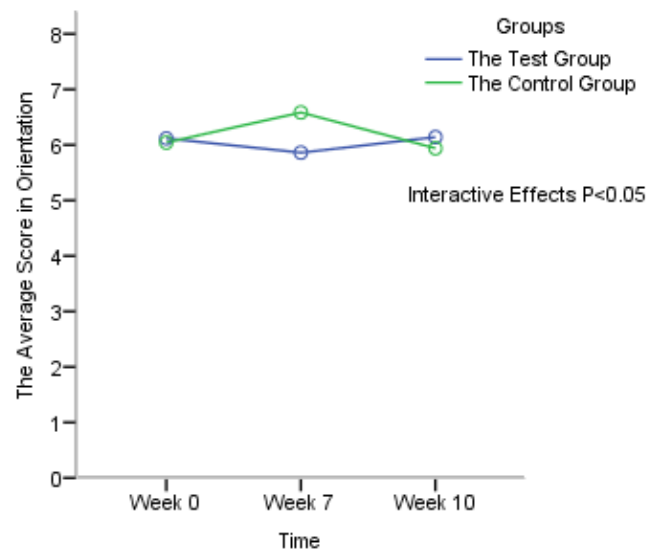
5.2 Comparisons of MMSE Scores between both two groups before and after the Intervention (Table6-4, Figure6-1)

Table 6-4. Comparisons of MMSE Scores between both two groups before and after the Intervention

MMSE	Week 0 ($\bar{\chi} \pm \varsigma$)	Week 7 ($\bar{\chi} \pm \varsigma$)	Week 10 ($\bar{\chi} \pm \varsigma$)	The Interactive Effects F (P) [#]	The Time Effects F (P) [#]	The Main Effects F (P) [#]
Orientation						
The Test Group	6.12 ±2.51	5.86±2.42	6.14±2.59	3.304 (0.039)	0.488(0.615)	0.101(0.751)
The Control Group	6.04±2.41	6.58±2.37	5.94±2.55			
Z (P)	-0.088 [♦] (0.930)					
Registration						
The Test Group	2.74±0.62	2.81±0.59	2.70±1.21	0.782 [△] (0.450)	0.020 [△] (0.974)	0.011(0.918)
The Control Group	2.75±0.64	2.71±0.80	2.83±0.60			
Z (P)	-0.198 [♦] (0.843)					
Attention and Calculation						
The Test Group	1.86±1.74	2.44±1.79	1.93±1.65	0.149(0.862)	6.456 ²⁾ (0.002)	0.016(0.900)
The Control Group	2.00±1.85	2.42±1.74	1.94±1.80			
Z (P)	-0.305 [♦] (0.760)					
Recall						
The Test Group	0.98±1.26	1.63±1.09	1.28±1.12			
The Control Group	1.46±1.15	1.71±1.09	1.90±1.13			
Z (P)	-2.005 [♦] (0.045)					
Language and Praxis						
The Test Group	7.02±1.58	7.72±1.53	7.84±1.27			
The Control Group	6.10±1.60	5.88±1.97	5.77±1.81			
Z (P)	-2.669 [♦] (0.008)					
Total						
The Test Group	18.72±4.85	20.47±5.75	19.77±5.57	1.354(0.261)	7.354(0.001)	0.783(0.379)
The Control Group	18.40±5.13	19.29±5.98	18.35±5.96			
Z (P)	-0.351 [♦] (0.726)					

Notes: [♦]Mann-Whitney U Test. [#]The analysis of repetitive variance measures.

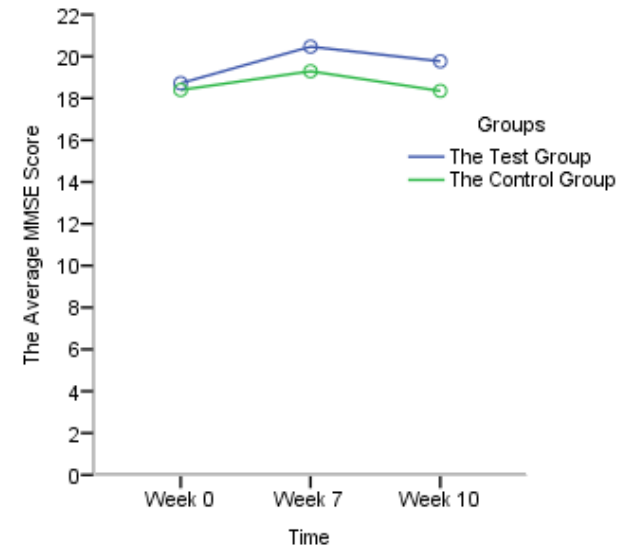
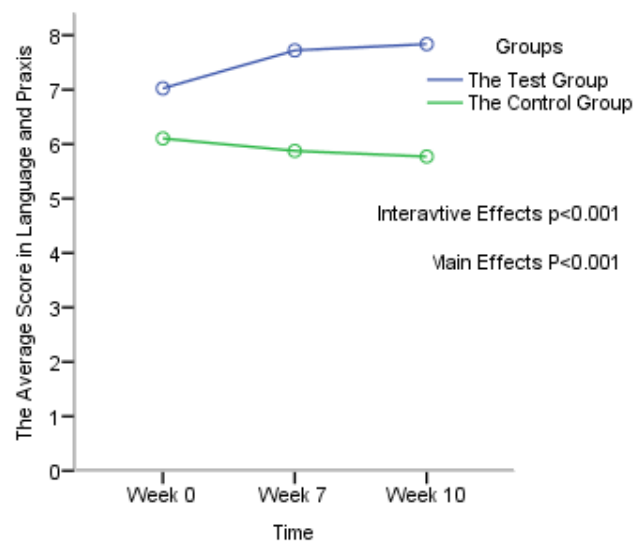
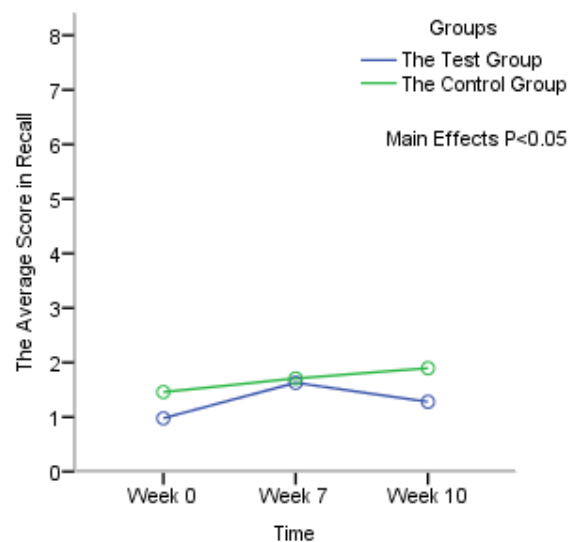
[△]Data not satisfying Sphericity Test, with Greenhouse-Geisser taken for correction coefficient.



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Figure 6-1. Effects of the Interaction between the Factors of Time and Grouping on MMSE scores

Comparisons of MMSE scores between both two groups before and after the intervention are shown in Table-6-4 and Figure 6-1.

6-4-Orientation

In week0, the intergroup difference was not significant by Mann-Whitney U test ($Z=-0.088$, $P=0.930$). The repeated measures analysis showed that there was no significant change with the time even if intervention time and intervention models interacted simultaneously. (The interactive effect $F=3.304$, $P=0.039$, the time effects $F=0.488$, $P=0.615$, the main effects $F=0.101$, $P=0.751$).

6-4- Registration

In week0, the intergroup difference was not significant by Mann-Whitney U test ($Z=-0.198$, $P=0.843$). The repeated measures analysis indicated that intervention models and intervention time haven't interacted simultaneously ($F=0.782$, $P=0.450$). Meanwhile, neither time nor different interventions had effect on "Registration." (The time effects $F=0.020$, $P=0.974$; the main effects $F=0.011$, $P=0.918$).

6-4- Attention and Calculation

In week0, the intergroup difference was not significant by Mann-Whitney U test ($Z=-0.198$, $P=0.843$). The repeated measures analysis showed that intervention time and intervention models haven't interacted simultaneously ($F=0.149$, $P=0.862$). Nevertheless, "Attention and calculation" score of the two groups changed with the time but had not relevant to the interventions.(The time effects $F=6.456$, $P=0.002$; the main effects $F=0.016$, $P=0.900$).

6-4- Recall

In week0, the intergroup difference was significant by Mann-Whitney U test

($Z=-2.005$, $P=0.045$). The two groups were not comparable on “Recall” so that the repeated measures analysis could not be carried on. However, in terms of the changing tendency, compared with week0, the test group increased 0.65 point in week7 and 0.3 in week10, while the control group increased only 0.25 in week 7 and 0.44 in week10.

6-4- Language and Praxis

In week0, the intergroup difference was significant by Mann-Whitney U test ($Z=-2.669$, $P=0.008$). The two groups were not comparable to do the repeated measures analysis on “Language and praxis” . But for varying of respective group, compared with week0, the test group rose 0.7 point in week7 and 0.82 in week10, while the control group lowered 0.22 in week 7 and 0.33 in week10.

6-4-Total

In week0, the intergroup difference was not significant by Mann-Whitney U test ($Z=-0.351$, $P=0.726$). The repeated measures analysis displayed that the intervention time and intervention models haven't interacted simultaneously ($F=1.354$, $P=0.261$) . The total score of MMSE of the two groups changed with the time and was not all about interventions. (The time effects $F=7.354$, $P=0.001$;The main effects $F=0.783$, $P=0.379$)

Overall, the intervention of two groups had not significant effect on the “Orientation”, “Registration”, “Attention and Calculation” and total score of MMSE although there was some time effect. In terms of intragroup comparison, the average score of “Recall” and “Language and Praxis” in test group had an increase tendency.

5.3 Comparisons of QOL-AD Scores between both two groups before and after the Intervention (Table6-5, Figure6-2)

Table 6-5. Comparisons of QOL-AD Scores between Both Two Groups before and after the Intervention

	Week 0 ($\bar{x} \pm s$)	Week 7 ($\bar{x} \pm s$)	Week 10 ($\bar{x} \pm s$)	The Interactive Effects F (P) #	The Time Effects F (P) #	The Main Effects F (P) #
QOL-AD						
The Test Group	29.14±5.63	32.33±6.47	31.33±5.48	10.688 (0.000)	3.355 (0.037)	0.917 (0.341)
The Control Group	30.98±5.16	30.13±5.96	28.65±6.25			
t (P)	-1.626 [*] (0.108)					

Notes: ^{*}Independent-Samples T Test. #The analysis of repetitive variance measures.

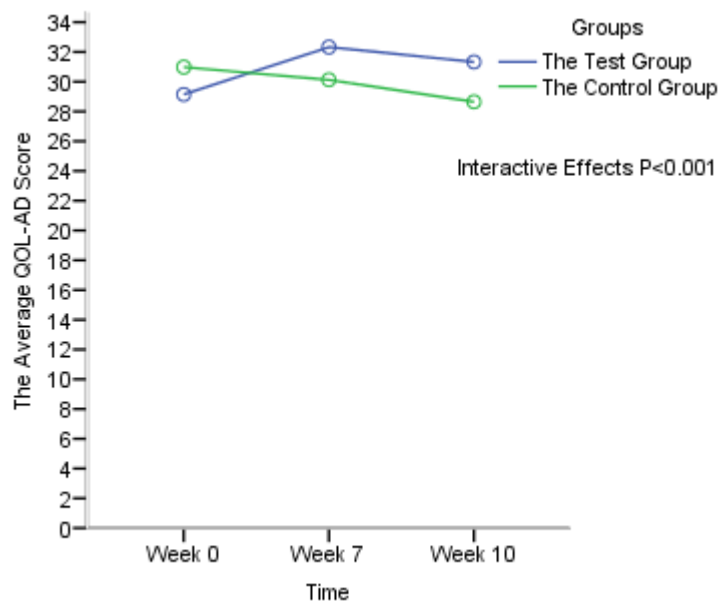


Figure 6-2. Effects of the Interaction between the Factors of Time and Grouping on QOL-AD scores

Comparisons of patients' QOL-AD scores between both two groups before and after the interventions were shown in Table 6-5 and Figure 6-2. Time taken into consideration, the two groups were comparable since there was no significant difference between participants' QOL-AD scores by T Test (by T test $T=1.626$, $P=0.108$) before the intervention (Week 0). The analysis of repetitive variance measures indicated that the differences of patients' QOL-AD scores at different time points before and after the intervention were statistically significant. (The interactive effect $F_{10.688}$, $P=0.000$; the time effects $F=3.355$, $P=0.037$). However, there was no significant difference between patients' QOL-AD scores in the Test Group and those in the Control Group ($F=0.917$, $P=0.341$). As shown in Figure 6-2, there was a more obvious rise of patients' QOL-AD scores in the test group followed by a slight decrease after the intervention. Patients in the test group score 2.68 marks higher than those in the control group a month after the intervention (Week 10). Interestingly, there was a trend of light decline in the control group in general, which is relatively difficult to explain clinically.

5.4 Comparisons of CSDD Scores between both two groups before and after the Intervention (Table 6-6, Figure 6-3)

Table 6-6. Comparisons of CSDD Scores between Both Two Groups before and after the Intervention

	Week 0 ($\bar{x} \pm s$)	Week 7 ($\bar{x} \pm s$)	Week 10 ($\bar{x} \pm s$)	The Interactive Effects F (P) #	The Time Effects F (P) #	The Main Effects F (P) #
CSDD						
The Test Group	3.79±2.57	2.26±2.49	2.86±2.22	0.516 [△] (0.581)	5.845 [△] (0.005)	6.455 (0.013)
The Control Group	5.04±4.03	3.44±3.26	4.90±6.24			
Z (P)	-1.269 [♦] (0.205)					

Notes: ♦Mann-Whitney U Test. #The analysis of repetitive variance measures.

[△]Data not satisfying Sphericity Test, with Greenhouse-Geisser taken for correction coefficient.

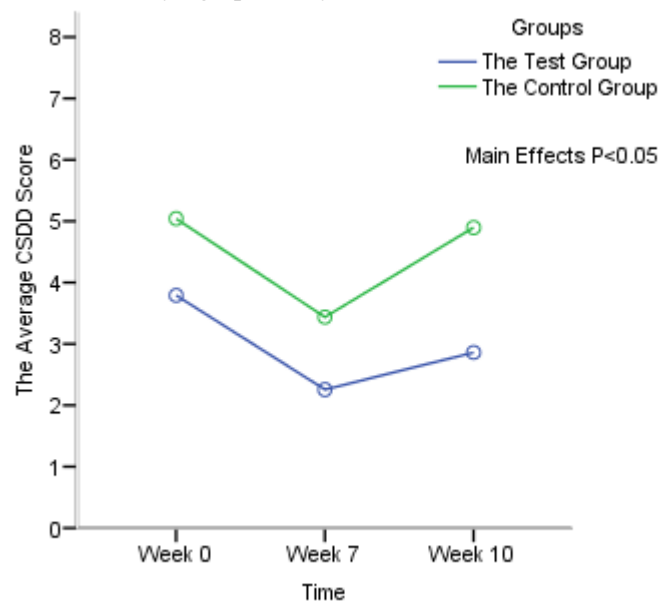


Figure 6-3. Effects of the Interaction between the Factors of Time and Grouping on CSDD scores

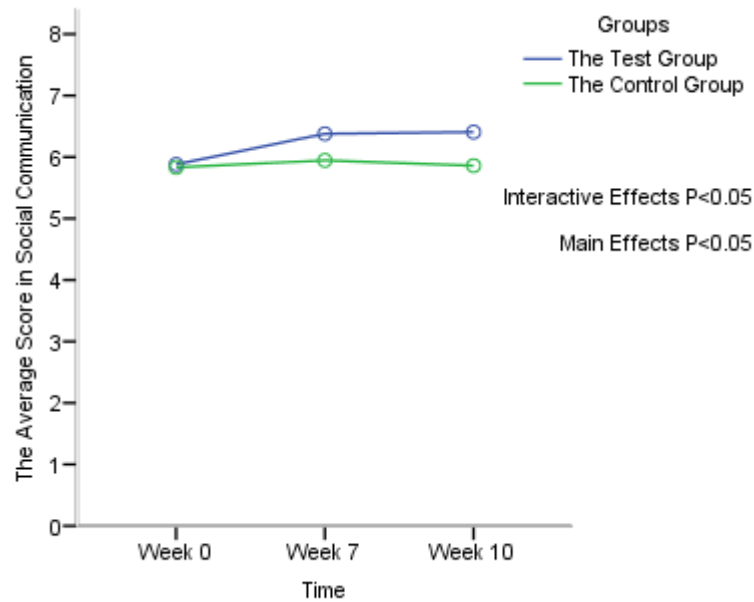
Comparisons of patients' CSDD scores between both two groups before and after the intervention were shown in Table 6-6 and Figure 6-3. In week0, the intergroup difference was not significant by Mann-Whitney U test ($Z=-1.269$, $P=0.205$). Although the repeated measures analysis indicated that intervention time and intervention models haven't interacted simultaneously (The interactive effects $F=0.516$, $P=0.581$), the total score of CSDD of the two groups changed with the time and the two intervention models had different effect significantly (The time effects $F=5.845$, $P=0.005$; the main effects $F=6.455$, $P=0.013$). It was appeared that both interventions may decrease the CSDD score, but the test group has a better maintenance of efficacy.

5.5 Comparisons of FACS Scores between both two groups before and after the Intervention (Table 6-7, Figure6-4)

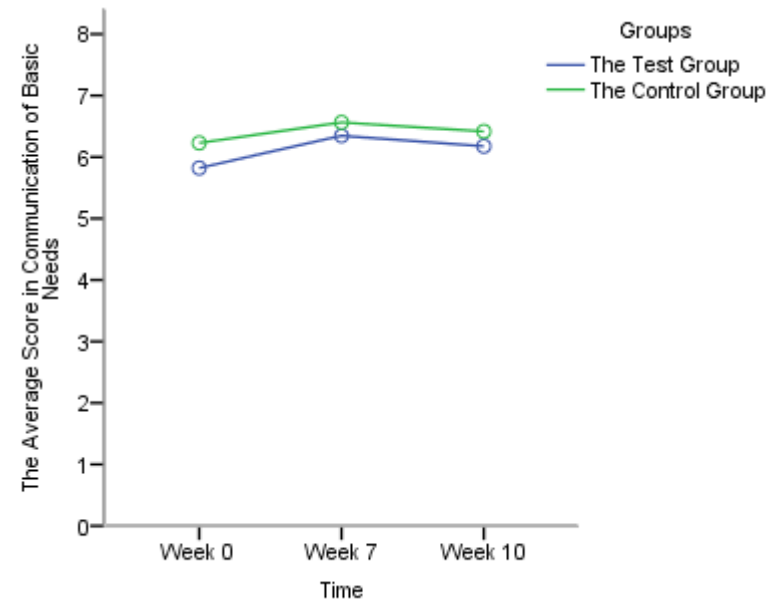
Table 6-7. Comparisons of FACS Scores between both two groups before and after the intervention

FACS	Week 0 ($\bar{\chi} \pm \varsigma$)	Week 7 ($\bar{\chi} \pm \varsigma$)	Week 10 ($\bar{\chi} \pm \varsigma$)	The Interactive Effects F (P) [#]	The Time Effects F (P) [#]	The Main Effects F (P) [#]
Social Communication						
The Test Group	5.88±0.96	6.38±0.77	6.41±0.77	4.523 (0.012)	7.585 (0.001)	6.113 (0.015)
The Control Group	5.83±0.85	5.94±0.81	5.86±0.69			
Z (P)	-0.417 [♦] (0.676)					
Communication of Basic Needs						
The Test Group	5.82±1.10	6.35±0.79	6.18±1.06	0.407 (0.666)	7.128 (0.001)	4.180 (0.044)
The Control Group	6.23±1.05	6.56±0.62	6.42±0.86			
t (P)	-1.815 [☆] (0.073)					

Notes: *Independent-Samples T Test. ♦Mann-Whitney U Test. #The analysis of repetitive variance measures.



1



2

Figure 6-4. Effects of the Interaction between the Factors of Time and Grouping on FACS scores

Comparisons of FACS scores between both two groups before and after the intervention are shown in Table 6-7 and Figure 6-4.

6-7- Social Communication

In week0, the intergroup difference was not significant by Mann-Whitney U test ($F=4.523$, $P=0.012$). The repeated measures analysis showed that the intervention time and intervention models interacted simultaneously, in other words, there is significant differences of patients' scores in social communication at any time point after the interventions statistically. ($P < 0.001$) (The interactive effect $F=10.688$, $P=0.000$) and the social communication score changed with the time by both intervention models (The time effects $F=7.585$, $P=0.001$). Furthermore, social communication score presented a significantly better improving effect in test group (The main effects $F=6.113$, $P=0.015$).

6-7- Communication of Basic Needs

In week0, the intergroup difference is not significant by T test ($t= -1.815$, $P=0.073$). The repeated measures analysis showed that though intervention time and intervention models hadn't interacted simultaneously (The interactive effect $F=0.407$, $P=0.666$), the score of communication of basic needs of the two groups changed with the time significantly (The time effects $F=7.128$, $P=0.001$). Also the increased range of the test group was significantly larger than another group (The main effect $F=4.180$, $P=0.044$).

5.6 Comparisons of ORES Scores between both two groups before and after the Intervention (Table 6-8)

Table 6-8. Comparisons of ORES Scores between Both Two Groups before and after the Intervention				
Types	Groups	n	$(\bar{x} \pm s)$	Z (P)
Pleasure	The Test Group	43	3.50±1.45	-2.908 (0.004) [♦]
	The Control Group	48	2.53±1.57	
General Alertness	The Test Group	43	4.99±0.76	-2.105 (0.035) [♦]
	The Control Group	48	4.73±0.67	

Notes: [♦]Mann-Whitney U Test.

The conclusion is drawn on the analysis of two average scores in the evaluation by OERS Scale at Week 3 and Week 6 which indicate emotional states of people with dementia during the activities in both two groups. The analysis is carried only on the scores in pleasure and general alertness, while not on their anger, anxiety/fear or sadness which are rarely observed. The results indicate that people with dementia in the test group score much higher in happiness during the activities by OERS Scale. People with dementia in the test group also score higher in the general alertness during the activities by OERS Scale and the differences are statistically significant. (Refer to Table 6-8)

6 Discussion

6.1 The meaningful of establishing Creative Story Therapy for people with dementia

With the deepening of China's ageing process, the prevalence of dementia is leading a rising trend year by year. According to the figures released by the Association of Chinese Alzheimer's in 2011, the prevalence rate has exceeded 6.6% among those with the age of 65 or above. Additionally, the rates double every 5 years after their 65-year-old, so that there is one suffered dementia of three in elderly citizens above 85-year-old (Wilson et al, 2002). Presently, reasons of dementia are unclear. Although drug treatment slows the disease progression possibly, dementia cannot be irreversible. As a result, promoting the life quality of people with dementia becomes the main task for treatment and healthcare (Lin et al, 2011). Based on researches from both domestic and foreign, taking part in events those activate neurons holds the positive effects of delaying the disease, in the meantime, it seems to be one of the protection factor against Alzheimer, and it will improve the quality of lives for people with dementia. Therefore, except for professional medical care, a series of appropriate intervention activities should also be provided, in order to maintain good mental and physical situations in people with dementia and help them get self-esteem, happiness as well as satisfaction in their twimild years. Consequently, this study adopts action research method to build the *Creative Story Therapy for People with Dementia* of China. Methods towards the elderly are suggested such as using intervening activities to stimulate their

intelligence and creativity in order to show their ability and talent, encouraging their contacts with others to improve interpersonal relationship, and improving their ability of expression for increasing their social interaction. These suggestions will help the aged acquire self-confidence as well as a sense of achievement, and take them away from loneliness, so that the quality of the elderly's life can be improved. At the same time, this research also provides information and reference for further studies in the future, and arouses more attention and support for Alzheimer's patients from the public.

6.2 The effects of creative story therapy to improve the cognitive function of people with dementia

According to the results of this study, by comparison MMSE test score before and after the intervention, the intervention of two groups have not significant effect on the "Orientation", "Registration", "Attention and Calculation" and total score of MMSE. In terms of intragroup comparison, the average score of "Language and Praxis" in test group had an increase tendency although this difference did not reach statistical significance.

This outcome was similar to the foreign studies. The damage of dementia patients' cognition is progressive, meanwhile, the physiological changes in the elderly's brain function and cognition also gradually recession. Besides, during the intervention treatment, the cognitions of people with dementia might decline because of illness factors at the same time. The sub-scale of language ability illustrated that improvement brought by creative storytelling therapy for people affected dementia was better than that of the general social activities. Although the significant change was not proved statistically, we could observe that during the whole process of TimeSlips activities, patients are encouraged to express creatively and their language skills have been promoted obviously.

Actually, improving dementia patients' cognition is one of the most fundamental treatments, but by far lots of drug and non-drug methods have little effect to it, including this study results. For this reason, many patients and their families think dementia cannot be cured, so they give up treatment and let things slide. In fact, this might probably adverse to the patient's rehabilitation, and

accelerate the deterioration. In recent society, dementia is not as hopeless as people usually considered. Once the reason of disease can be diagnosed, around 10% patients will be treated completely. Drug therapy and non-drug therapy methods may not completely cure for dementia, but at least they might delay late severe symptoms of dementia and provide certain help to people with dementia.

6.3 Effects from creative expression therapy to improve the quality of life of people with dementia

Results from this study presented that compared with general social activities the creative storytelling intervention had little obvious influences on improving the mild, moderate dementia patients' life quality. The quality of life scale rating is based on the subjective feelings of dementia patients, so the score might be affected by many aspects, such as recent events, the disease getting better or worse, a dispute with others, sleep, diet, etc. That may explain the declining trend in the control group. Besides, the improvement or decline of quality of life is a long-term process while the intervention lasted only six weeks. Furthermore, because of affected by disease directly or indirectly, the life quality of people with dementia is generally low. As a result, it is difficult to improve dementia patients' life quality significantly in a short period. Nevertheless, the comparison results within groups display that life quality scores in the test group led a rising trend, which demonstrates the difference is statistically significant. Due to the damage of cognitive function in people with dementia, they tend to experience the unfortunate part of lives in illness, so they have difficulty obtaining successful feeling. However, according to related researchers, when dementia patients can realize their own value, they will acquire positive emotion and mood, so that their quality of lives could be advanced. In the meantime, influences of dementia symptom bring like disorders in patients' body, behaviour and mental may cause rejections from family, staff or other health senior citizens, which will probably make negative experiences and undesirable feelings accumulated to dementia patients. Consequently, acceptance and respect is the primary element during creative expression therapy to people affected dementia. This is because patients can understand and confirm their own value gradually when they are accepted and

respected, so they have the chances to feel happiness of lives and success, finally their life qualities will be facilitated. In general, it is vital to improve the quality of life to patients with dementia, despite the process is slow and painstaking, and the key is providing acceptance, respects, empathy and compassion to them.

6.4 Effects of creative expression therapy to relieve the depressive symptoms of people with dementia

The data from this study illustrated that It was appeared that both intervention may decrease the CSDD score but compared with general social activities group, the test group has a better maintenance of efficacy. Nowadays, the high incidence of depression in the elderly cannot be ignored, and according Barua and his colleagues' (Lin, X.L., et al, 2011) Meta analysis, the morbidity in the elderly with dementia is 10.3%. Moreover, among senile chronic diseases, especially neural degeneration diseases, the incidence of depression is higher. Contrasted with elder people without dementia, people affected dementia have a higher incidence of depression. Consulting a study, the incidence of depression is up to 87% in AD patients (Di Iutia F, 2010), while the percentage is 70.8% in another domestic research(Xiang, 2014). In recent years, studies on the impact of depression on prognosis of dementia are numerous. They give evidences that depression will not only delay the recovery of nerve function defect or cognitive impairment, but also increase the mortality of cerebrovascular disease, and finally reduce the quality of patients' life and their life satisfaction. Therefore, in the research of dementia, relieving patients' depressive symptoms are important to ensure patients' compliance and research's progress smoothly. This study confirms that creative expression therapy can significantly reduce mild, moderate dementia patients so that patients' quality of life could be enhanced, with depressive symptoms, which has similar effects to other non-drug therapy research results.

Study revealed that participating activity was an important factor to decrease the depression(Liu,2014). During this study, those who haven't taken part in the activities were living a boring and changeless life in the institution , eating, sleeping,receiving treatment, watching TV, strolling and so on. That would be

not benefit for depression remission but aggravate the symptoms. On the other hand, the evidence has been approved that the depression often resulted in descending of social status and decreasing of self-care ability, which lead to self-abased and feeling of uselessness. Those people unable to meet the social role and finally appear depress symptoms. The TimeSlips gave the participants a new social role- the creative storytelling, which made people with dementia responsible for the role so as to perceive self value and release the symptoms.

Although the changing trend of CSDD score show that general social attention and creative expression treatment of depression in patients with mild and moderate dementia symptoms have certain advancement, there might still exist some deviation. Because to measure depressive symptoms of patients depended on the nurse, staffs or patients' family, they might be subjective.

6.5 Effects from creative expression therapy to relieve the communication ability of people with dementia

The research displayed that both Social Communication and Communication of Basic Needs were affected significantly by TimeSlips. The conclusion is consistent to research results in the USA.

Creative expression therapy is patients guided by the host telling stories, so its main content is to express in verbal or nonverbal way, in order to exercise patients' communication ability. Besides, in the process of specific creative storytelling therapy, staffs were expected to adopt appropriate skills, such as call the roll, encourage, support, positive reinforcement and etc. In specific, calling the roll can help patients focus their attention, encouraging them to try for their positive expression, providing support in time to make them gradually reduce the vigilance and self-abased psychology. Every a bit of progress of the patients with encouragement and giving appropriate reward was to remind them feel progress and change they make by themselves. These interventios could benefit for people with dementia communicating actively with others. When dementia patients' communication skills have improved, they will be able to express their needs more clearly and make requirements, which would

reduce the burden on caregivers. Additionally, the programme can also promote the communication of patients with others, establish good relationships, and let more people establish face-to-face relationships in daily life, which have certain positive influence on people affected dementia to solve relationship problems and alleviate their adverse feelings such as loneliness, sadness and so on.

6.6 Effects of creative expression therapy to relieve the emotional condition of people with dementia

According to the research, both creative expression therapy and general social attention stimulate people with dementia to result in main emotional performance, happy and general alarm, but patients accept creative storytelling therapy with higher scores of happy mood and general alert sentiment compared to the group undergoing general social concern.

Dementia patients are often not understood or rejected, even by their families, staff and other health elderly people. Under these circumstances, people should pay attention to and care about them, so they will show positive emotions naturally. Creative storytelling therapy like the general attention of society pay attention to and care about dementia patients, in addition, it also gives patients the initiative. For instance, in the process of activities, patients with dementia is a storyteller, and curers are listeners who give positive response in time, which let patients feel affirmed and popular. Therefore, the patient's negative mood will disappear gradually, and replaced by happy, general alarm and other positive emotions.

6.7 The continued effect of creative expression treatment

Results of the study have shown that the scores after four weeks' intervention in test group like CSDD, FACS simple social communication dimension are significantly different with the scores before the intervention. The implementation of creative storytelling therapy in people with dementia after 6 weeks, depressive symptoms as well as simple social communication ability not only could be enhanced, but also the effect can stay four weeks after the intervention stops.

The two most profound aspects of continuing effects are the total treatment time and interval time of stimulating. However, the duration is not absolutely proportional to the stimulus. If stimulus time is infinite, it can transfer effective stimulus to invalidate even malignant stimulation, so any non-drug therapy's treatment timing should have rationality. Besides, illness has its law of development and the body's response to the stimulus is different, hence the trend of stimulated effect from creative expression therapy in different time presents ups and downs. According to this, time limit of creative expression therapy is expected to explore, because when a stimulus gradually decay, another one should give immediately again. Establishing reasonable creative expression therapy time interval and selecting the appropriate intervention time again have important guiding significance to extend the therapy effect of continuous creative expression therapy. For this, foreign scholars mainly implemented once a week for ten weeks and two times a week for six weeks, and this study refers the latter one.

6.8 The advantages of creative expression therapy compared with other non-drug therapy

For the past few years, domestic researchers have attempted a series of non-drug therapy for dementia patients, including music therapy, cognitive training, nostalgia method, game therapy, daily living skills training, etc. These therapies' main purpose is to improve cognitive function in patients, delaying their dementia progress, thus their quality of life can be promoted. However, the non-drug therapy also has insufficiency, for they are focusing on the abilities those dementia patients are losing or have lost, which could remind the deterioration of patients or give them memory pressure, and sequentially patients' emotions may suffer a negative impact. By contrast, the creative storytelling therapy focus on patients' creativity and potential, and it replaces the memory pressure by encouraging patients' imagination and creative potential. Furthermore, due to the certain curative effect, simple operation, economical and practical characteristics, creative expression therapy is favorably received by many dementia care institutions and researchers overseas. Additionally, practical skills of creative storytelling therapy are also

reasons of its popularity.

(1) Acceptance: individual patients have some physical, behavioral and mental disorders because of the influence of the disease, so activity perpetrators should understand their behavior, take the acceptant attitude to them believe their own ability and strength, and believe they have the ability of growing continuously, learning, sharing and creating.

(2) Do not criticism: activity carriers should keep an open attitude to patients with dementia, do not to judge, and encourage patients imagining, creating and expressing, no matter their answers are right or wrong.

(3) Positive reinforcement: rewarding and encouraging patients' every bit of progress in the activities by perpetrators properly can make patients reduce their vigilance and self-abasement gradually, and let them be aware of their progress and change.

Chapter 7: Conclusion

This study was accomplished to validate feasibility and validity of the creative storytelling intervention through the 7 rounds action research and quantitative evaluation study by means of observation, interview and questionnaire. Eventually the creative storytelling intervention protocol for the patients with dementia in China was established, providing for hospitals, communities and nursing homes. The researchers have participated in whole process of action research and understood that creative expression intervention was able to reset a social role for the PWD rather than general recreational activities. The social model of care puts patients with dementia within the context of their social circumstances (Gilliard *et al.*, 2005). The care givers try to understand the emotions and behaviours of the person with dementia by learning about individual history and background, thus care and support can be designed to be more appropriate to individual needs.

Results of the study suggested that TimeSlips increased cognition and better verbal communication for the people with mild and moderate dementia in treatment group, compared with the control group who participated in normal social activities. Although the differences of cognitive ability and quality of life between these two groups were not statistically significant, and it is worthy to mention that the quality of life experienced an upward tendency in the late treatment phase. As such, the treatment group exhibited significant decline in depression as well as better communication, higher pleasure and general alertness in the patients with mild and moderate dementia during the intervention. In addition, researchers found that after 6-week programme, the effect of improvements in depression and simple social communication could persist for 4 weeks follow-up.

Philips and his peers (Philips, 2010) had conducted a research to randomize controlled trials from 28 cases of elderly patients with dementia with creative expression therapy, while the other 28 cases of routine nursing. The conclusion is that creative expression therapy has a positive effect ($P < 0.05$)

on patients with Alzheimer's mood and communication ability, and also has certain effect on depressive symptoms of the patients, but the results did not reach the statistically significant level. Although this study is different from Phillips et al. study of design, for example, Phillips' research design is more rigorous and strictly follow the principle of random sampling, random grouping experiments. This study only takes the convenience sampling method, but the sample size is relatively larger than Phillips', and results found are similar. Moreover, Fritsch (2009) adopted the convenience sampling methods, he selected 10 nursing home (nursing home, a common old institutions in the United States, for the treatment and pension) with dementia care units in two states, and randomly divided them into two groups: test group with 10 weeks' creative expression therapy one time of one week, while the control group with routine nursing intervention. After the intervention, qualitative investigation is undergoing. The study show that compared with control group, test group patients become more active, positive, and the direct interaction, communication and contact frequency between patients and nursing staff are more frequent. Daniel also acquired the similar results (Daniel, 2014) .On this basis, in order to study the influences creative expression therapy taken for moderate and severe patients' communication ability, Bahlke chose 7 cases of moderate and severe dementia patients to experiment creative expression therapy, and with the help of time series analysis to evaluate the change of patients' communication and social interaction (Bahlke, 2010). The consequence illustrate that the creative expression therapy can facilitate moderate and severe dementia patients' social contact and interaction. This study as well as numerous abroad studies all proved that creative storytelling therapy will benefit elderly patients with dementia, especially for their oral communication, social interaction and emotional state. However, none of above research considered the social attention bias in the control group except this study.

In sum, creative storytelling intervention could effectively not only improve PWD's competency of cognition, communication and quality of life, but also decrease depression and negative mood. Moreover, this working pattern combined research with practice, so as to enhance the practical nursing work,

meanwhile promote the clinical staffs to participate in research and thus solve the current nursing problems.

Limitations and future research

In considering potential limitations of this study, several features may be relevant in interpreting study findings. Firstly, the size of study sample was relatively small. In China, the population of the elderly with dementia is considerably increasing, while health service resources from the public medical institutions and community-based agencies are too limited to meet the healthcare need, resulting that the majority of patients with dementia have to dispersedly receive family caregiving, and only those patients coexisting with organic diseases are hospitalized. Therefore, due to the time limitation, only the subjects who met the inclusion criteria in Fuzhou City were selected in the study, and it was hard to attain larger sample size, random sampling and grouping. In addition, most facilities where recruited PWD lack of specialized dementia ward in Fuzhou City, so more large-sample, multi-center researches are still needed to study in the future.

Secondly, considering that the participants need to have certain ability to understand and communicate, it is a limitation of the study design that the participants were the patients with mild and moderate dementia, not including those with advanced dementia who had been verified the effects in abroad. Therefore, with greater resources, more domestic researches are suggested to conduct in further.

Thirdly, the delivery of TimeSlips intervention was only six consecutive weeks, which is similar with foreign researches, but the study findings may be limited and the effect initiating time can not yet be determined in Chinese population. It is important to train caregivers in LTC settings, regularly implement the creative storytelling intervention for patients with dementia so as to continuously improve the quality of life of patients. According to the results from foreign research, this intervention not only can facilitate communication and mutual understanding between the patient and the caregiver, but also

change the caregivers' attitudes toward patients with senile dementia, establish a good relationship between them, as well as improve the pension agency atmosphere. The effects of this study will be verified and discussed in the follow-up research.

Lastly, the mechanism of the intervention was not discovered whether the foreign research nor studies in China.

Researchers' experiences

(1) Focus on patients with Alzheimer's diseases

The process of aging in China is accelerating since China entered the aging society in 1999. According to the data released by the Ministry of Health of China, the prevalence of dementia in persons over 60 was 4.2%, and dementia has become the second leading cause of elderly mental health hazard. So, we should work together to focus on this particular older age groups, aiming at arousing more attention toward them. Faced with this problem, we should deepen the understanding of dementia, and offer more care and support. Clearly, TimeSlips is proved to be a creative method that encourages storytellers with dementia to improve creativity and social interaction, and turn away from negative emotions, thus enhances their quality of life.

When delivering the program, we found the treatment participants not only retained the capacity of creativity, but also owned wealthy life experience, so they had great potentials related improvement, study and sharing, meanwhile, the experiences behind the stories also enlighten us greatly. By interactions, on the one hand, we held more positive views on PWD, and improved communication skills, which is important for person-centered care. On the other hand, this approach improves caregivers' ability and professional knowledge, thus to shorten the gap between theory and practice is priority for clinical nurses. Moreover, patients with dementia often suffer from social isolation as well as physical and mental disabilities and had to rely on caregivers, as a result they may lose the ability of self-expression and

self-esteem. Therefore, we need to encourage the elderly to participate in more positive activities so as to slow disease progression and kill their loneliness, thereby improving their quality of life.

(2) Application of strength perspective in geriatric nursing

Theoretical basis of creative storytelling intervention is based on concept of humanistic care, and the interaction with dementia is proceeded in a “no blamed”, “no error answer” principle. Currently strength perspective is advocated in social welfare settings. It emphasizes the importance of the patients’ initiative and new cooperative relationship established between care receivers and care givers during the service. The reshaped relationship might correct professional hegemony consciousness of welfare professional staffs, and encourage them to build a receivers-oriented idea, so as to better understand the feedback from service receivers. Taiwan scholars also stressed that "strength perspective" would have a far-reaching impact on nursing work (Mei, 2005). Her study found that elder people have a wealth of experience in lives, they still have infinite possibilities to grow and develop their potential capacities. Thus, if the strength perspective applied in geriatric nursing, a trust relationship would replace the traditional simple between care and be-care relationship. Standing on the equal position, the elderly can feel they are respected and acknowledged.

(3) Application of intergenerational learning in geriatric nursing

Intergenerational learning refers to the interactive activities between the younger generation and the elderly in the learning process, it encourages younger people to cultivate a positive attitude towards the elderly, and share experiences of different ages. Throughout creative storytelling intervention, we find it can enhance nursing students ‘empathy and communicating skills with the elderly, and cultivate their positive attitude towards the elderly, so as to improve their nursing abilities. Therefore, practice of intergenerational learning can be a important issue in geriatric nursing teaching.

Recommendations

(1) Recommendations for improving the quality of nursing institution for the aged

This study employs action research method to establish a sound work mode of TimeSlips Creative Storytelling Intervention in the elderly with dementia. Results of the study show that TimeSlips can effectively promote patients' creativities, self-expression and verbal communication skills, as well as present positive interaction and less negative emotions, thus improve quality of life and maintain cognitive function. Apparently, it is feasible to strongly propose that creative storytelling intervention can be widely applied in the treatment of dementia in the elderly healthcare institutions to improve service quality for the aged.

This program brings a series of benefits. Initially, for institutional managers, the results of this study can be used as a reference for related activities. Facility staff can include nurses, social workers, volunteers and family members. In the meantime, they can simultaneously be provided with some related courses and seminars, which help them to be quality and professional. Furthermore, for caregivers, trouble from the patients' unusual behaviors plus lack of language about the disease of dementia may affect their working outcomes to some extent. Gratifyingly, TimeSlips program provided a new channel of communication between the patients and caregivers, which can deepen mutual understanding, enhance interaction and share happiness, and also increase caregivers' total job satisfaction. In addition, social resources should be effectively utilized in the absence of actual healthcare resources. Related organizations, schools and social communities should cooperate to promote non-drug interventions in patients with senile dementia, which can partly relieve the pressure from manpower and funding shortage.

(2) Recommendations for the construction of China's system of elderly care service

According to the Plan for the Social Service System for the Aged (2011-2015), released by Chinese government, the social service system aims for satisfying

the needs of care services and enhancing the quality of life for the elderly, building a strong network including facilities, organizations, personnel and techniques, providing the elderly with everyday life care, rehabilitation care, spiritual comfort, emergency rescue and social participation. Moreover, the old-age welfare service system should be based on the family supply, supported by the community welfare service and supplemented by the social welfare organizations. Therefore, the results of this study will be used as reference for intervention activity in patients with dementia. It is suggested that more accessible community service should be offered for the aged, and more day-care centers and home-based care project will be established so as to promote the widespread use of TimeSlips at home, community and organizations as well as provide the elderly with social participation and spiritual comfort , which is a far-reaching package of measures to not only enhance the quality of life of elderly with dementia, but also effectively alleviate caregivers' strain and stress.

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Appendixes

Appendix I Demographic Characteristic Questionnaire

Code number _____

MMSE score: _____

Admission Number: _____ Admitted date: _____

Namer : _____ Gender: _____ Age : _____ Education Status: _____

Clinical diagnose: _____

Is there any complication? _____

Is there any difficulty on eating? _____

Self-care Competency:

☐ wholly self-care ☐ partly self-care ☐ completely ☐ dependent

The main caregivers _____

Living Status:

☐ live lonely ☐ with families

☐ with caregivers ☐ with family and caregivers

Marital Status:

☐ married ☐ unmarried ☐ widowed ☐ divorced

Living place: ☐ urban ☐ countryside

Habitual language:

☐ mandarin ☐ Fuzhou dialect ☐ other dialect _____

Does the Hearing affect dialogue? ☐ Yes ☐ No

With help of hearing-aid: ☐ Yes ☐ No

Does the eyesight affect reading? ☐ Yes ☐ No

With help of glasses: ☐ Yes ☐ No

Monthly income:

☐ below 1000Yuan ☐ 1000-3000Yuan ☐ more than 3000Yuan

Payment status: ☐ Medical insurance ☐ ☐ pocket payment ☐ Others _____

Address: _____

Contact persons : _____

Relationship with patients : _____

Telephone : _____

Appendix II Informed Consent Form

Purpose of the database

TimeSlips programme on dementia developed in the past three years in the USA are leading to positive changes on cognitive competency, community skill, and quality of life, etc. of mild and moderate dementia. At the same time, they are opening new perspectives in the field of scientific research.

Likewise, current techniques and those to be developed in the future might help us better slow the dementia progress. This is why we try to explore the new programme to be suitable on Chinese people with dementia that allow the development of specific research as well as new therapeutic methods for people with dementia. However, we will not be able to reach this goal if people with dementia and their relatives are not be willing to take part in the research and do not consent that their clinical records will be stored, preserved in appropriate conditions and used for further research.

Procedures

If you agree to participate in this project, you will participate the TimeSlips programme twice a week for 6 consecutive weeks. The programme will be held in a public group meeting room. You are seated surrounding a facilitator and a funny photograph is distributed to you. In group storytelling, you try your best to image and tell the story. This study honored participants' preference to attend or not on any given day. The one-hour sessions were held two afternoons a week with groups of people with dementia.

Clinical records concerning your changes will be documented and stored. It is our aim to develop this activity with the respect due to individual rights in accordance with the internationally accepted ethical rules, ensuring you that all the research to be carried out will be under the supervision of an Ethical Committee, that will ensure the observance of the mentioned regulations.

For the above reasons we request your voluntary collaboration.

Access to your data

The research team might require for the development of the research to collect your data to get information necessary for the evaluation.

Identification of the record

We will preserve the confidentiality of the records that will be marked with a code. The information will be stored, coded and anonymously handled by the researchers, but the participant could be identified through a code which access will be restricted to the database administrator. Thus the records will be anonymously handled by the researchers. De-codification will only be made by the database administrator or by a person expressly appointed by the researcher.

Length of storage

Clinical information will be kept for a 5-year period.

Benefits

This is an altruistic donation, therefore no economic compensation should be obtained by the donor. However, we expect that results obtained from this

research will enable us to improve the knowledge on dementia and finally may result in useful benefits for society as a whole.

Physical risks

No physical risks are expected.

Confidentiality

The collected data will be governed by the regulations on data protection policy. Both the information gathered from you and research results will be confidentially treated. The information will be codified. Data obtained will only be published in an anonymous and aggregated way, that is to say, as percentages or numerical data without identification of the participant, never in an individualized way to prevent his/her identification.

Third-party access to the results.

Unless you have provided specific authorization your personal results will not be made available to third parties such as employers, governmental organizations, insurance companies or educational institutions. This also applies to your spouse, other members of your family and your physician.

Freedom of participation and right of withdrawal

Participation in this project is voluntary. Law of Data Protection grants the right of access, the participant to rectify or withdraw. Should you wish to withdraw your data from the database you will be free to do so without further explanation. You should get in touch with the person responsible for the research.

Contact persons

Should you need additional information regarding the programme or wish to communicate any time to us, you can contact the person responsible for the programme at the following phone number:

Professor Li Hong: mobile phone, 8613705070219

Final words

Mrs Li Hong explained the nature of programme. I have fully understood the consent form and have received a copy. I have had the opportunity to ask questions that have been answered. Upon reflection, I agree to participate in this programme.

People with dementia signature: _____

Signature Date: _____

Telephone: _____

If the people with dementia is unable to sign informed consent, requesting authorization relatives in this signature:

Relatives of people with dementia with authorized signature: _____

Relationship with people with dementia: _____

Signature Date: _____

Telephone: _____

Appendix III Observing Form

Activity date/time				
1)Be willing to participate 0=refuse to participate 1=need persuading to participate 2=need reminding to participate 3=participating without any press				
2)Attention 0=complete absence of mind during the activity 1=concentrating time totally<10min 2=concentrating time totally 10-20min 3=concentrating time totally 20-30min				
3)Ability to express 0=express confusedly and intangibly 1=only a few words 2=express relatively integrated content with help 3=express integrated content independently				
4)communication 0=not involved in talking 1=only answer questions 2=can respond other participants 3=can initiate a topic				
5)level of involvement 0=completely not responding 1=noncooperation/seldom involving 2=involving actively with incentive 3=involving actively without any incentive				
6)level of enjoyment 0=no sign to indicate enjoyment 1=intermittent happiness 2=enjoy most time of the activity 3=enjoy all the activity time				
7)mood 0=unhappy 1=general2=happy 3=others (document: sad,angry,anxious,fear,etc.)				
8)total speech number of times				
9)total speech time				

Source:

Lai Jingyu, Mo Jingming. Reminiscence Therapy.The Hong Kong Society for Rehabilitation. <http://www.rehabsociety.org.hk/2002>

Appendix IV semi-structure interview outline

1 Interview to the people with dementia

- (1) Could you talk about your feeling in the activities?
- (2) Have you had any changes from the beginning to now? Please give an example.
- (3) Could you tell me the reason of change?
- (4) Could you tell me whether the activity had any influence in your life? Please give an example.
- (5) Which activity has impressed you most? Or In which activity did you have best performance?
- (6) Do you feel the activity suitable for you? Could you give us any suggestion?

2 Interview to the observer and collaborator

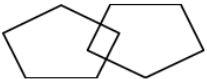
- (1) What changes and influence of the elderlies' life after the activities? Please take an example.
- (2) What factors attribute those changes?
- (3) During your observing, what have you found the changes of people with dementia in respect of involving, communicating, emotion, attention, etc.?
- (4) Could you please give a reflective comment on the programme, advantages vs disadvantages and suggestion?
- (5) Could please tell something most impressed you? Have you had any changes on your behaviours and views to people with dementia.

Appendix V Mini-Mental State Examination (MMSE)

Mini-Mental State Examination (MMSE)

Patient's Name: _____ Date: _____

Instructions: Score one point for each correct response within each question or activity.

Maximum Score	Patient's Score	Questions
5		"What is the year? Season? Date? Day? Month?"
5		"Where are we now? State? County? Town/city? Hospital? Floor?"
3		The examiner names three unrelated objects clearly and slowly, then the instructor asks the patient to name all three of them. The patient's response is used for scoring. The examiner repeats them until patient learns all of them, if possible.
5		"I would like you to count backward from 100 by sevens." (93, 86, 79, 72, 65, ...) Alternative: "Spell WORLD backwards." (D-L-R-O-W)
3		"Earlier I told you the names of three things. Can you tell me what those were?"
2		Show the patient two simple objects, such as a wristwatch and a pencil, and ask the patient to name them.
1		"Repeat the phrase: 'No ifs, ands, or buts.'"
3		"Take the paper in your right hand, fold it in half, and put it on the floor." (The examiner gives the patient a piece of blank paper.)
1		"Please read this and do what it says." (Written instruction is "Close your eyes.")
1		"Make up and write a sentence about anything." (This sentence must contain a noun and a verb.)
1		"Please copy this picture." (The examiner gives the patient a blank piece of paper and asks him/her to draw the symbol below. All 10 angles must be present and two must intersect.) 
30		TOTAL

Interpretation of the MMSE:

Method	Score	Interpretation
Single Cutoff	<24	Abnormal
Range	<21	Increased odds of dementia
	>25	Decreased odds of dementia
Education	21	Abnormal for 8th grade education
	<23	Abnormal for high school education
	<24	Abnormal for college education
Severity	24-30	No cognitive impairment
	18-23	Mild cognitive impairment
	0-17	Severe cognitive impairment

Interpretation of MMSE Scores:

Score	Degree of Impairment	Formal Psychometric Assessment	Day-to-Day Functioning
25-30	Questionably significant	If clinical signs of cognitive impairment are present, formal assessment of cognition may be valuable.	May have clinically significant but mild deficits. Likely to affect only most demanding activities of daily living.
20-24	Mild	Formal assessment may be helpful to better determine pattern and extent of deficits.	Significant effect. May require some supervision, support and assistance.
10-19	Moderate	Formal assessment may be helpful if there are specific clinical indications.	Clear impairment. May require 24-hour supervision.
0-9	Severe	Patient not likely to be testable.	Marked impairment. Likely to require 24-hour supervision and

Source:

Folstein, M.F., Folstein, S.E. & McHugh, P.R. (1975) Mini-mental state: A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res*, 12, 189-198.

Source:

www.medicine.uiowa.edu/igec/tools/cognitive/MMSE.pdf

Provided by NHCQF, 0106-410

Appendix VI Quality of Life: AD

Interview Version for the people with dementia

ITEM	poor	fair	good	excellent
1. Physical health.				
2. Energy.				
3. Mood.				
4. Living situation				
5. Memory.				
6. Family.				
7. Marriage.				
8. Friends.				
9. Self as a whole				
10. Ability to do chores around the house.				
11. Ability to do things for fun.				
12. Money.				
13. Life as a whole.				

Comments: _____

SCORING INSTRUCTIONS FOR THE QOL:

Points are assigned to each item as follows:

poor=1, fair=2, good=3, excellent=4.

Appendix VII The Functional Assessment of Communication Skills (FACS)

Subtests		Measurement							
I Social Communication									
1.Refers to familiar people by name		7	6	5	4	3	2	1	N
2.Requests information of others		7	6	5	4	3	2	1	N
3.Explains how to do something		7	6	5	4	3	2	1	N
4.Expresses agreement/ disagreement		7	6	5	4	3	2	1	N
5.Exchanges information on the phone		7	6	5	4	3	2	1	N
6.Participates in group conversation		7	6	5	4	3	2	1	N
7.Answers yes/no questions		7	6	5	4	3	2	1	N
8.Follows simple verbal directions		7	6	5	4	3	2	1	N
9.Understands non-literal meaning and inference		7	6	5	4	3	2	1	N
10.Smiles or laughs at lighthearted comments		7	6	5	4	3	2	1	N
11.Understands non-literal meaning and inference		7	6	5	4	3	2	1	N
12.Understand conversations when they occur in noisy		7	6	5	4	3	2	1	N
13.Understand what's heard on TV and radio		7	6	5	4	3	2	1	N
14.Understand facial expressions		7	6	5	4	3	2	1	N
15.Understands tone of voice		7	6	5	4	3	2	1	N
16.Initiates communication with other people		7	6	5	4	3	2	1	N
17.Adds new information on a topic in a conversation		7	6	5	4	3	2	1	N
18.Changes topics in conversation		7	6	5	4	3	2	1	N
19.Adjusts to a change in topic by conversational		7	6	5	4	3	2	1	N
20.Recognizes his/her own communication errors		7	6	5	4	3	2	1	N
21.Corrects his/her own communication errors		7	6	5	4	3	2	1	N
Qualitative Dimensions									
Social Communication	adequacy	appropriateness			Promptness		communication sharing		
II Communication of basic needs									
22.Recognizes familiar faces		7	6	5	4	3	2	1	N
23.Recognizes familiar voices		7	6	5	4	3	2	1	N
24.Makes strong likes or dislikes known		7	6	5	4	3	2	1	N

25.Expresses feelings			7	6	5	4	3	2	1	N
26.Requests help when necessary			7	6	5	4	3	2	1	N
27.Makes needs or wants known			7	6	5	4	3	2	1	N
28.Responds in an emergency			7	6	5	4	3	2	1	N
Qualitative Dimensions										
Communication of basic needs	adequacy	Appropriateness	promptness				communication sharing			
III Reading, Writing, Number Concepts										
29.Understands simple signs			7	6	5	4	3	2	1	N
30.Uses common reference materials			7	6	5	4	3	2	1	N
31.Follows written directions			7	6	5	4	3	2	1	N
32.Understands basic printed material			7	6	5	4	3	2	1	N
33.Prints/writes/types name			7	6	5	4	3	2	1	N
34.Fills out short forms			7	6	5	4	3	2	1	N
35.Writes messages			7	6	5	4	3	2	1	N
36.Understands signs with numbers			7	6	5	4	3	2	1	N
37.Makes basic money transactions			7	6	5	4	3	2	1	N
38.Understands simple units of measurement			7	6	5	4	3	2	1	N
Qualitative Dimensions										
Reading, Writing, Number Concepts	adequacy	Appropriateness	promptness				communication sharing			
IV Daily Planning										
39.Knows what time it is			7	6	5	4	3	2	1	N
40.Dials telephone numbers			7	6	5	4	3	2	1	N
41.Keeps scheduled appointments			7	6	5	4	3	2	1	N
42.Uses a calendar for time-related activities			7	6	5	4	3	2	1	N
43.Follows a map			7	6	5	4	3	2	1	N
Qualitative Dimensions										
Daily Planning	adequacy	Appropriateness	promptness				communication sharing			

This tool contains 43 items divided into four communication domains: Social Communication, Communication of Basic Needs, Reading Writing and Number Concepts, and Daily Planning. Each item is rated on a 7-point scale. In addition, each of the four communicative domains is rated on four 5-point qualitative scales for Adequacy, Appropriateness, and Promptness, which reflect the frequencies with which the respective dimensions are shown during communication(ranging from “never”to “always”), while the last scale, called Communicative Sharing, indicates the extent of the burden to the communicative partner(ranging from “all” to “equal”).

Qualitative dimensions

- (1) Adequacy: Frequency with which client understands gist of message and gets point across.
- (2) Appropriateness: Frequency with which client’s communication is relevant and done under the right circumstances.
- (3) Promptness: Frequency with which client responds without delay and in an efficient manner. Communication Sharing: Extent to which a client’s communication poses a burden to the communication partner.
- (4) Communication Sharing: Extent to which a client’s communication poses a burden to the communication partner.

Source:

Frattali, C., Thompson, C., Holland, A., et al. (1995) *The American Speech- Language- Hearing Association functional assessment of communication skills for adults (ASHA FACS)*. Rockville MD: ASHA.




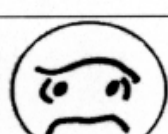

Appendix VIII Observed Emotion Rating Scale

OBSERVED EMOTION RATING SCALE

RESIDENT'S NAME _____ UNIT: _____ OBSERVER'S NAME: _____ DATE: _____ TIME: _____

Please rate the extent or duration of each affect over a ten-minute period. Some possible signs of each emotion are listed.

If you see no sign of a particular feeling, rate "Never."

		7	1	2	3	4	5
		Not in view	Never	Less than 16 sec.	16-59 sec.	1-5 min.	more than 5 min.
PLEASURE Signs: Laughing; singing; smiling; kissing; stroking or gently touching other; reaching out warmly to other; responding to music (only counts as pleasure if in combination with another sign).							
ANGER Signs: Physical aggression; yelling; cursing; berating; shaking fist; drawing eyebrows together; clenching teeth; pursing lips; narrowing eyes; making distancing gesture.							
ANXIETY/FEAR Signs: Shrieking; repetitive calling out; restlessness; wincing/grimacing; repeated or agitated movement; line between eyebrows; lines across forehead; hand wringing; tremor; leg jiggling; rapid breathing; eyes wide; tight facial muscles.							
SADNESS Signs: Crying; frowning; eyes drooping; moaning; sighing; head in hand; eyes/head turned down and face expressionless (only counts as sadness if paired with another sign).							
GENERAL ALERTNESS Signs: Participating in a task; maintaining eye contact; eyes following object or person; looking around room; responding by moving or saying something; turning body or moving toward person or object.							

Appendix IX The protocol of creative storytelling treatment

The purpose of the programme

For people with dementia, the programme aims to improve cognitive and communicating competence as well as to build self-esteem.

1. Assessing before the activity

Participants:

The participants who have mild or moderate impaired cognitive competency should have the ability to understand and speak mandarin or dialects, hearing adequate to hear the programme dialogue, eyesight adequate to view the programme stimulus images. Every activity may group 6-10 elders with dementia, more participants in case of more facilitators.

Assessment

To collect the baseline condition the facilitators should consult from the charts, communicated with the people with dementia, families, care givers and primary nurses. The data comprise disease condition, communicating ability, educational level, characteristic of personality, interests, etc. Also physical and mental state before and in the course of every activity should not be overlooked.

Activity time and duration

At every turn, the activity may take 30 minute to 1 hour. It is important to consult the people with dementia and care givers of their activity time to avoid conflicting with their treatment plan and daily schedule.

2. Preparation for the activity

1. Implementers:

The conductors were ready for their responsibilities. The programme need 1 facilitator who invite and lead the storytelling, 1 recorder to write down all the answers and responds on the whiteboard with a marking pen. Beside, some assistants or care givers are need to help the elders communicate, go to toilet and other demand for operability and safety.

2.Site and space preparation

To ensure the site is easily accessible to. The space should be relatively bright and quiet without distractions. It is better to put the chairs in a semi-circle and enables the group to see each other, leaving space between them in case the facilitators need to move right next to someone in order to be heard.

3.Materials

Some materials should be prepared, such as images, name tags, markers, white board or paper big enough to be seen, microphone if necessary. The image is the core of the activity. There are some requirements for the images:

①images can invite a story; ②images should not be too busy; ③images can be either B/W or color; ④images should be the size of a sheet of regular paper to be easily seen. However, except for these requirements, the facilitator had to consider the Chinese culture and the education background of the participants to choose some photos from magazine or internet. The images could be a new scene they have never met or seen, but not far away from their life. They also might be a familiar phenomenon but not looked like “real” family photos to prompt reminiscence rather than to prompt imagination. The photos are best not to be weird and tedious otherwise they could say nothing even might indulge in a low mood.

3. The process of the activities

4.Preliminary stage

(1)Every time before the intervention, the implementers invite the participants initially and remind them to bring glasses and hear-aids, and then wearing their name tags.

(2>Welcome the storytellers to the activity.

(3)The facilitator introduce him/her self and the activity purpose and meaning as well as process. The first time should be given more time for the participants to know each other well. Some calm and leisurely old songs may promote emotional communications.

(4)Review the story from the previous session.

This step may help the participants remind the process of the activity and understand their role of activity again.

5. Main stage

(1) Select a new image

Before the start, the elders could select an interesting photo from 2-3 prepared images and every participant owned a same image every time so as to keep it in mind.

(2) Ask open-ended questions.

The facilitator applied “open-ended” question to encourage imagination and individual expression. The questions could be 5W1H , (When, Where, Who, What, Why and How), which related to the image content directly. Besides the questions could also jump outside the image but relevant to the theme. Meanwhile, the assistants convey the information repeatedly and timely in order to avoid ignoring anyone.

(3) Echo all responses and retell the story

The implementers try to write down all responses to let the storyteller know they had been heard and understood. In necessary, retell the story purposefully to refocus the storytellers. The facilitators should equally keep a watchful eye on every participant rather than only some outstanding performance.

(4) Build to a final retelling.

To weave and share the story again, the facilitator state the whole story and try to give a topic of the story.

6. Ending stage

(1) When the elders feel tired of the storytelling, the facilitator concludes the activity in time. Then appreciating the elders’ engagement and praising the outstanding performance.

(2) To remind the time and site of next activity

(3) To say good-bye to the elders.

(4) To reflect and conclusion activity every time to improve the programme.

Points for attention

Appendix X Images Kit

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